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Original Article

Quality of Life in Children With Chronic Kidney Disease Using the Hindi Version of PedsQL 3.0 End-stage Renal Disease Module: Perspective of Patient and Caregiver

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ABSTRACT

Background and Aim: Limited data exists on health-related quality of life (HRQOL) in children with chronic kidney disease (CKD) stage 5D and the results often differ. This study assesses the HRQOL in children with CKD stage 5D using the Hindi version of the paediatric quality of life (PedsQL) 3.0 end-stage renal disease module.

Methods: This was a cross-sectional, questionnaire-based study conducted between February 2018 and January 2019 at a tertiary-care center in New Delhi, India. HRQOL was assessed in 45 children (age=5-18 years) receiving maintenance dialysis for at least 2 months, using both child self-report and parent-proxy report.

Results: Enrolled children had poor HRQOL, with the worst scores observed in the treatment-problems (TP) domain (child and parent-proxy report). Patients who were on hemodialysis had lower quality of life (QOL) scores compared to subjects on peritoneal dialysis, especially in the TP domain. We found a significant negative impact of adolescent age group (general fatigue [GF], about-my-kidney-disease [AMKD], family and peer interaction [F/PI]), female gender (perceived physical appearance [PPA]), rural residence (total, GF, AMKD), separated parents (AMKD, worry), lower maternal education (GF, communication), higher number of medication intake (AMKD, F/PI), low hemoglobin (communication) and more number of hospitalizations in last six months (F/PI) on HRQOL of enrolled children. Furthermore, the child-reported mean total scores in the domains of GF, TP, F/PI and worry were less favorable compared to parent-reported scores. School attendance was seen in only 15 % of the children.

Conclusion: End-stage kidney disease exerts a significant impact on the HRQOL of affected children; therefore, comprehensive management of this disease in children should include QOL assessment.

Keywords: Chronic kidney disease (CKD), Dialysis, Kidney failure, Quality of life (QOL), Paediatric quality of life (PedsQL)

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Introduction

With the advancement of medical care, children with kidney failure have now improved long-term survival. As a result, more children are living with the burden of long-term chronic illness and reaching adult age [1]. Chronic kidney disease (CKD) affects almost every organ system, having a major impact on mortality and quality of life (QOL) [2]. The physical and psychosocial impact of the disease process and its management make CKD-5D a particularly challenging condition with symptoms like malaise and lethargy, stringent dietary restrictions, multiple medications and their adverse effects, repeated hospital visits for dialysis and investigations, changes in physical health due to complications and psychological problems, such as anxiety, depression and altered body-image [3]. The definition of success in the care of pediatric CKD-5D patients should not be limited to mortality rates but must include the degree to which these children are allowed to grow, develop and behave in the same manner as their healthy peers [4].

Limited data exists on health-related QOL (HRQOL) in children with CKD-5D, and results often differ [1]. Moreover, the use of varying tools to measure QOL has made results difficult to compare. Additionally, in most of the studies involving the families of CKD-5D patients, either the children or their parents/caregivers were examined without taking into account their interrelationships [5]. One study showed no difference in perceived QOL among children on dialysis and the general population [6]. On the contrary, others have reported HRQOL in children on dialysis to be significantly lower compared to healthy controls [1, 5, 7-9].

Overall, few studies have assessed HRQOL in pediatric nephrology patients from India and only one study evaluated children with CKD [9, 10]. Hence, this study assesses the HRQOL of children with CKD-5D between 5 and 18 years, using the Hindi version of the paediatric quality of life (PedsQL) 3.0 end-stage renal disease (ESRD) module (child self-report and parent proxy report) and evaluates the effects of sociodemographic and disease characteristics.

Materials and Methods

Study design and participants

This was a cross-sectional, questionnaire-based study conducted between February 2018 and January 2019, after approval from the institutional Ethics Committee and review board. Children aged 5-18 years who received maintenance dialysis treatment for at least 2 months and their parents were recruited from the Pediatric Nephrology Clinic at Sir Ganga Ram Hospital, New Delhi, India. Children were excluded if they had a history of hospitalization within 14 days (except for dialysis), change in dialysis modality within the past 30 days, severe to profound mental retardation, congenital heart disease, or any other chronic illness, and those with significant life event unrelated to their kidney disease in past 30 days (for instance death of a family member). Informed consent was obtained from parents/caregivers of all the children. For children older than 7 years, assent was also obtained.

Study measures

Baseline clinical and sociodemographic details of the participants were collected, including age, sex, cause of CKD, time since diagnosis of CKD, modality of dialysis, etc. Health-related QOL (HRQOL) was assessed using the PedsQL inventory™ 3.0 ESRD module (Hindi-for-India version) once at the time of clinic visit, using child self-report and parent-proxy report [11]. The questionnaire was administered by the principal investigator for children, while parents/caregivers completed the questionnaire independently in a separate room. Each tool was piloted in 10 cases and 10 controls before study initiation. Each measurement required up to 30 min to be completed. The recall time was one month.

PedsQL™ 3.0 ESRD module is composed of 34 items comprising 7 dimensions, namely general fatigue (GF; 4 items), about my kidney disease (AMKD; 5 items), treatment problems (TP; 4 items), family and peer interaction (F/PI; 3 items), worry (10 items), perceived physical appearance (PPA; 3 items), and communication (5 items). This measure includes child self-report (age=5–18 years) and parent proxy report (age=2-18 years). Scores range from 0 to 100 points, with higher scores indicating better QOL. Each item asks the respondent to rate to what extent a certain condition has been a problem in the past month using a five-point Likert scale from 0 to 4 (0=never, 1=almost never, 2=sometimes, 3=often, 4=almost always). For younger children (5–7 years), a simplified three-point pictorial scale is used for child self-reporting. The scores of each item are then reversed and linearly transformed into a 0–100 scale (0=100, 1=75, 2=50, 3=25, and 4=0). Based on the instructions provided, scores for each dimension were calculated as the sum of the items divided by the number of items answered. If more than 50% of the items in the scale were missing,

the scale score was not computed. The total scores were calculated as the sum of the items divided by the number of items answered on all the scales [1, 11].

Statistical methods

Categorical data were presented as frequencies and percentages while continuous variables were expressed as Mean±SD or median and interquartile range as appropriate. The student t-tests and analysis of variance tests were used for bivariate analyses of independent categorical variables with the PedsQL 3.0 ESRD mean scores. A comparison of PedsQL 3.0 ESRD mean scores between child self-report and parent proxy report was also performed. Scale internal consistency reliability was determined by calculating the Cronbach α coefficient. Scales with reliabilities of 0.70 or higher are recommended for comparing patient groups, whereas a reliability criterion of 0.90 is recommended for analyzing individual patient scores.

Intra-class correlation (ICC) with a 95% CI was used to measure the agreement between pediatric patient self-report and parent proxy-report scores for each domain of the PedsQL. Agreement between child self-report and parent-proxy report was determined through a two-way mixed-effect model (absolute agreement, single measure) ICC. The ICC values were classified as poor (≤0.40), moderate (0.41–0.60), good (0.61–0.80), or excellent (0.81–1.00) [12]. Statistical testing was conducted with the SPSS software, version 22 (IBM Corporation Armonk, NY, USA).

Results

Sample characteristics

A convenience sample of 45 children, aged 5-18 years and their parents were included in the study. Table 1 presents the baseline characteristics of the study cohort. The majority of the study participants (mean age 11.5±4.3 years) were males (n=37[82%]) and in the 8-12 years age group (n=19[42.2%]). Only 7(15.5%) participants were enrolled in the school. The most common cause of CKD-5D was congenital anomalies of the kidney and the urinary tract/urologic causes (n=20 [44.4%]), with most of them (n=38[84.4%]) diagnosed more than a year before inclusion in the study. The Mean±SD duration since the diagnosis of CKD and initiation of dialysis were 59.5±52.9 months and 26.9±15.9 months, respectively. Most of the included subjects were on hemodialysis (HD) (n=24[53.3%)], had hemoglobin (Hb) values ≥11 g/dL (n=32[71.15%]) and ≤1 hospitalization (n=31[68.9%]) in the last 6 months. Of the 45 children included, 22(44.4%) had one or more comorbidities at the time of enrolment.

QOL

Table 2 lists the child and parent-reported PedsQL ESRD 3.0 scores and their respective discrepancies. The child reported mean total scores (<0.001) and in the domains of GF (P=0.001), TP (P=0.004), F/PI (P=0.002), and worry (P=0.002) were significantly lower than the parent-reported scores. No statistical difference was found between child and parent-reported scores in the domains of AMKD, PPA and communication.

Child report

On bivariate analysis of the child-reported PedsQL ESRD 3.0 scores (Table 3), the mean AMKD scores were significantly different (P=0.006) across all age groups with the lowest (52.7±24.1) scores in children between 13-18 years and highest (74.2±12.7) among 8-12 years age group. F/PI was impacted maximally (40.9±19.8) in 5- to 7-year-olds compared to other age groups. Subjects belonging to rural areas had significantly lower mean total (52.8±12.7 vs 61.7±13.9), as well as GF (44.7±28.6 vs 69.9±19.3) domain scores compared to those living in urban areas. No effect of family size, socioeconomic status, and school enrollment was noted.

Children of divorced/separated parents had statistically lower AMKD (64±20.7 vs 82.5±8.7) and worry scores (54±22.2 vs 71.9±7.2) compared to individuals whose parents were living together. Those children whose mothers were ≥40 years of age were significantly more likely to have lower AMKD scores (62.2±22.1, P=0.032); however, more communication difficulties (45.4±22.5, P=0.014) were observed among children of younger mothers (<40 years). Significantly lower GF (51.8±24.7, P=0.042) and communication scores (52.5±20.4, P=0.037) were seen among children of mothers with lower education level (high school or below), whereas, only lower GF scores (43.2±26.9, P=0.013) were noticed among children whose fathers had lesser education. Patients who were on HD had lower QOL scores (36.9±30.6 vs 54.4±24.9) in the TP domain, compared to those on peritoneal dialysis (PD). No effect of other parameters (fathers' age, family history of renal disease, underlying cause of CKD, time since first diagnosis of CKD, time since first dialysis, number of medications, Hb level, number of hospitalizations in past 6 months) was observed.

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Table 1. Baseline characteristics of included children and parents

Characteristic		No. (%)	Mean±SD
Age (y)	5-7	11(24.4)	11.5±4.3
	8-12	19(42.2)	
	13-18	15(33.3)	
Sex	Male	37(82.2)	
	Female	8(17.8)	
Residence	Rural	19(42.2)	
	Urban	26(57.8)	
Socioeconomic class[a]	I-III	21(46.7)	
	IV-V	24(53.3)	
Family size (persons)	≤4	17(7.8)	
	>4	28(62.2)	
Enrolled in school	Yes	7(15.5)	
	No	38(84.5)	
Family status	Parents living together	41(91.1)	
	Parents separated	4(8.9)	
Mothers' age group (y)	<40	13(28.9)	
	≥40	32(71.1)	
Mothers' education level	High school or below	24(53.3)	
	Higher Secondary or above	21(46.7)	
Fathers' age group (y)	<40	10(22.2)	
	≥40	35(77.8)	
Fathers' education level	High school or below	12(26.7)	
	Higher secondary or above	33(73.3)	
Family history of renal disease	Yes	4(8.9)	
	No	41(91.1)	
Primary cause of CKD	Congenital anomalies of the kidney and the urinary tract/urologic causes	20(44.4)	
	Chronic glomerulonephritis	9(20)	
	Cervical intraepithelial neoplasia	4(8.9)	
	Uremic syndrome	2(4.4)	
	Genetic	4(8.9)	
	Unknown	6(13.3)	
Time since 1st diagnosis of CKD (m)	≤12	7(15.6)	59.5±52.9
	>12	38(84.4)	
Time since 1st dialysis (m)	≤12	11(24.4)	26.9±15.9
	>12	34(75.6)	
Modality of renal replacement therapy	Peritoneal dialysis	21(46.7)	
	Hemodialysis	24(53.3)	
Number of medications	<5	10(22.2)	
	≥5	35(77.8)	
Hb level (g/dL)	<11	13(28.9)	
	≥11	32(71.1)	
Number of times hospitalized in the past six months[b]	≤1	31(68.9)	
	>1	14(31.1)	
Comorbidity[c]	Yes	20(44.4)	
	No	25(55.6)	

[a]BJ Prasad classification 2019 [13], [B]Other than for dialysis; [c]Including neurological diseases, liver diseases, cardiac, gastrointestinal and endocrinological disorders, genital malformations and visual problems.

Table 2. Cronbach α coefficients and mean PedsQL 3.0 end stage renal disease module scores (child self-report and parent-proxy report)

Parameter		India (n=45) Dialysis			Mean±SD						
		Mean±SD	P	α	USA (n=174-189) Dialysis+Transplant [1]	USA (n=56-68) Dialysis [17]	Korea (n=6) Dialysis+Transplant [2]	UK (n=9) Dialysis [14]	Egypt (n=25) Dialysis [7]	Sub-saharan Africa (n=27) Dialysis [15]	Singapore (n=19) Dialysis [16]
GF	Child	59.3±26.5	0.001	0.812	72.4±21.9	72.4±23.9	59.0±21.7	52.1±22.1	55.0±19.8	66.7±19.8	57.9±27.2
	Parent	69.9±24.7		0.908	68.3±24.0	59.5±23.2	46.6±22.2		54.8±26.6	64.4±21.6	
AMKD	Child	65.7±20.6	0.790	0.757	70.4±17.8	67.9±18.9	65.5±19.4	60±10.9	58.8±16.2	63.5±18.3	62.1±17.5
	Parent	65.1±18.5		0.629	71.3±19.4	64.4±18.3	62.6±19.9		53.4±14.8	61.3±21.1	
TP	Child	45.1±29.2	0.004	0.790	74.2±18.6	71.1±20.2	64.1±18.9	66.7±17.1	58.7±23.7	62.5±18.7	55.6±24.5
	Parent	56.5±26.4		0.709	72.3±19.9	64.6±21.1	64.9±18.3		48.5±26.9	66.6±20.4	
F/PI	Child	50.2±21.2	0.002	0.669	73.9±25.2	64.8±27.1	62.0±22.6	51.9±25.6	51.0±25.7	50.0±23.6	57.9±24.1
	Parent	63.5±22.3		0.529	72.2±24.6	64.9±27.2	52.5±23.6		61.7±22.7	53.5±33.1	
Worry	Child	55.7±21.8	0.002	0.818	70.6±21.6	66.9±23.2	60.9±22.2	64.2±18.1	59.3±19	50.7±18.1	50.9±21.7
	Parent	66.7±24.7		0.929	74.6±19.6	67.8±21.9	46.4±22.5		53.0±16.1	53.4±21.9	
PPA	Child	69.6±18.7	0.713	0.626	72.0±26.2	72.7±25.2	59.3±26.8	81.5±24.6	54.3±30.6	50.9±19.4	57.0±24.6
	Parent	70.9±23.7		0.647	74.4±25.7	73.8±23.9	51.5±25.9		56.7±26.5	52.2±25.0	
Communi-cations	Child	60.0±25.9	0.252	0.704	74.3±24.9	74.1±23.5	72.7±20.9	73.9±15.4	55.2±23.3	65.0±19.4	61.8±19.1
	Parent	62.7±29.3		0.753	73.2±26.9	67.5±28.9	72.3±20.6		49.2±27.4	75.4±25.6	
Total	Child	57.9±14	0.000	0.856	-	-	62.3±17	64.4±10.5	56.8±13.3	57.9±12.1	56.7±15.5
	Parent	65.1±14.7		0.919			56.7±16.5		53.3±12	60.5±15.4	

Abbreviations: AMKD: About my kidney disease; F/PI: Family and peer interaction; GF: General fatigue; PPA: Perceived physical appearance; TP: Treatment problems; SD: Standard deviation.

Parent report

Parent-reported QOL scores (Table 4) in the domains of GF, AMKD, and F/PI were significantly different across all the age groups-highest in 8- to 12-year-olds and lowest in the 13-18 years age group. Female participants had significantly lower PPA scores than males (56.3±12.4 vs 74.1±24.4). Children residing in rural areas had lower QOL compared to urban children, especially in the AMKD category (58.7±15.6 vs 69.7±19.4). Younger mothers (<40 years) reported statistically lower communication scores (46.2±19.3 vs 69.4±30.2) in their children than those ≥40 years of age. Worry scores were lower among children with smaller families (55.8±31, ≤4 members vs 73.3±17.6, >4 members), whereas, communication skills were impacted in children belonging to larger families (54.6±27.7, >4 members vs 75.9±27.7, ≤ 4 members). Children of mothers with lower education (high school or below) had poorer QOL in the communication domain (53.3±25.3 vs 73.3±30.3) compared to subjects of mothers with higher education. Children taking a greater number of medications (≥5) for supportive treatment had significantly lower AMKD (62.1±17.7 vs 75.5±18.5) and F/PI scores (75.8±14.4 vs 60±23). No effect of the underlying cause of CKD and modality of renal replacement therapy (RRT) was noted. Anemic children (Hb<11g/dL) had poorer communication scores (50.3±19.6 vs 67.7±31.2), while more number of hospitalizations (>1) in the previous 6 months resulted in lower QOL in F/PI (52.4±19.7 vs 68.5±21.8).

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Table 3. PedsQL™ 3.0 end stage renal disease module mean scores (child self-report) by characteristics

Variables		GF		AMKD		TP		F/PI		Worry		PPA		Communication		Total	
		Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P
Age	5-7 8-12 13-18	55.7±28.3 69.7±13.8 48.8±33.4	0.060	68.6±18.8 74.2±12.7 52.7±24.1	0.006	47.2±31.3 42.1±20.6 47.5±37.4	0.843	40.9±19.8 61.4±15 42.8±23.3	0.007	56.6±22.8 59.2±17.4 50.7±26.2	0.533	65.2±15.3 76.3±21.3 64.4±15.5	0.122	56.4±21.7 52.4±28 72.3±22.9	0.070	55.8±12.4 62.2±9.1 54.2±18.9	0.216
Sex	Male Female	59.6±28.4 57.8±16.6	0.812	65.4±21.1 66.9±19.4	0.857	45.6±29.8 42.9±27.6	0.819	51.3±23.1 44.8±6.2)	0.143	54.4±22 61.9±21.1	0.386	69.6±20.1 69.8±10.9	0.979	60.8±28.2 56.3±10.6	0.451	58.1±15.1 57.2±7.2	0.799
Residence	Rural Urban	44.7±28.6 69.9±19.3	0.002	61.3±19.4 68.8±21.2	0.229	41.8±30.8 47.6±28.2	0.515	43.4±18.5 55.1±21.9	0.067	55.4±21.2 55.9±22.7	0.930	66.7±14.2 71.8±21.5	0.370	56.6±23.7 62.5±27.7	0.457	52.8±12.7 61.7±13.9	0.035
Socioeconomic class	I-III IV-V	65.2±20.4 54.2±30.4	0.157	66.4±21.5 65±20.2	0.819	46.4±26.7 44.1±31.6	0.785	50±22.1 50.3±22.9	0.957	50.9±22.2 60±20.9	0.163	69.1±21.9 70.1±15.9	0.848	58.8±27.1 61±25.5	0.778	58.1±13.4 57.8±14.8	0.945
Family size	≤4 >4	64.7±19.9 56±29.7	0.293	63.2±22.9 67.1±19.3	0.543	40.1±24.9 48.2±31.5	0.370	50±23.4 50.3±20.2	0.964	50.7±22.9 58.8±20.9	0.235	67.2±22.9 71.1±15.9	0.496	67.6±24.8 55.4±25.9	0.125	57.7±13.4 58.1±14.6	0.912
Enrolled in school	Yes No	62.2±22.5 57±29.6	0.521	62.8±21.6 68±19.8	0.401	46.3±24.1 44.3±33.2	0.816	47±24.2 52.7±18.6	0.386	49.8±22.8 60.5±20.1	0.100	63.8±21.3 74.3±15.2	0.059	65.8±23.9 55.4±27.1	0.187	56.7±14.4 58.8±13.9	0.624
Family status	Parents together Parents separated	58.1±27.3 71.9±11.9	0.327	82.5±8.7 64±20.7	0.011	44.8±29.6 48.4±27.7	0.817	49.6±21.6 56.3±18.5	0.555	71.9±7.2 54.2±22.2	0.005	68.5±18.9 58.3±14.2	0.397	61.1±26.6 48.8±17	0.370	57.2±14.4 65.8±6.1	0.242
Mothers' age group	<40 ≥40	62.5±23.2 58±28	0.612	74.2±13.5 62.2±22.1	0.032	50±24.7 43.2±30.9	0.482	53.8±18.8 48.6±22.2	0.467	59±18.9 54.4±23.1	0.518	73.0±17.6 67.9±19.2	0.357	45.4±22.5 65.9±25.2)	0.014	59.8±8.7 57.2±15.7	0.480
Mothers' education	≤High school ≥Higher secondary	51.8±24.7 67.9±26.5	0.042	65.4±18.5 65.9±23.1	0.932	38.1±26.2 53.3±30.8	0.080	47.6±15.6 53.2±26.3	0.400	58.4±18.5 52.7±25.2	0.395	68.8±16.5 70.6±21.3	0.740	52.5±20.4 68.6±29.3	0.037	54.6±10.1 61.7±16.9	0.103
Fathers' age group	<40 ≥40	65±19.8 57.7±28.2	0.448	73±14.9 63.5±21.6	0.205	51.8±21.9 43.2±30.9	0.414	50.8±19.8 50±21.8	0.914	59.5±18.6 54.6±22.7	0.542	73.3±17.5 68.5±19.8	0.485	51.5±20.6 62.4±27.1	0.245	60.7±8.4 57.2±15.3	0.345
Fathers' education level	≤High school ≥Higher secondary	43.2±26.9 65.2±24.2	0.013	62.1±21.4 66.9±20.5	0.487	34.4±28.6 49.1±28.7	0.137	44.4±17.2 52.3±22.4	0.279	58.9±20.2 54.62±22.5	0.577	68.7±15.9 69.9±19.8	0.852	52.1±21.8 62.8±27.1	0.222	51.9±9.7 60.1±14.8	0.084
Family history of renal disease	Yes No	40.6±29.9 61.1±25.9	0.142	63.7±16 65.9±21.1	0.848	48.4±35.9 44.8±28.9	0.816	35.4±14.2 51.6±21.3	0.147	51.9±19.7 56.1±22.2	0.715	60.4±12.5 70.5±19.1	0.308	50±21.6 60.9±26.3)	0.426	50.1±7.8 58.7±14.3	0.243

Variables		GF		AMKD		TP		F/PI		Worry		PPA		Communication		Total	
		Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P
Time since the 1st diagnosis of CKD (m)	≤12 >12	68.6±13 57.6±28.1	0.311	71.4±24.9 64.6±19.8	0.426	33.9±20.7 47.2±30.2	0.273	50±26.4 50.2±20.5	0.980	49.23±22.3 56.9±21.8	0.401	63.1±32.2 70.8±15.5	0.321	58.6±27.3 60.2±26.1	0.876	56.4±12.8 58.2±14.4	0.760
Time since1st dialysis (m)	≤12 >12	70.5±21.3 55.7±27.3	0.110	69.5±17.9 64.4±21.5	0.478	49.4±29.2 43.8±29.4	0.580	53.8±27.5 49±19.1	0.523	55.7±24.6 55.8±21.2	0.993	71.9±24.8 68.9±16.7	0.639	54.1±30.8 61.9±24.4	0.392	60.7±14.5 57.1±13.9	0.459
Modality of renal replacement therapy	Peritoneal dialysis Hemodialysis	63.7±24.4 55.4±28.2	0.305	69±20.6 64.4±21.4	0.308	54.4±24.9 36.9±30.6	0.043	53.5±18.9 47.2±23	0.322	55.4±18.9 56.1±24.4	0.921	71.8±15.7 67.7±21.2	0.468	63.1±24.1 57.3±27.7	0.461	61.5±12.7 54.8±14.6	0.105
No. of medications	<5 ≥5	63.7±26.8 58.1±26.7	0.554	66.5±13.1 65.4±22.4	0.850	45±26.1 45.1±30.3	0.987	51.6±24.4 49.7±20.5	0.805	53.5±16.2 56.3±23.3	0.718	69.2±25.7 69.7±16.7	0.946	58±25.1 60.5±26.5	0.786	58.2±11.3 57.8±14.8	0.945
Hg level (g/dL)	<11 ≥11	50.9±28.2 62.6±25.5	0.182	62.3±19.6 67.1±21.1	0.492	48.1±29.6 43.9±29.4	0.675	42.9±20.1 53.1±21.2	0.147	49.6±16.3 58.2±23.5	0.235	71.8±17.8 68.7±19.2	0.627	52.6±19.1 62.9±28	0.166	54.1±10.1 59.5±15.1	0.239
No. of times hospitalized (past 6 months)	≤1 >1	58.7±27.8 60.7±24.3	0.814	68.9±17.9 58.6±24.8	0.121	46.2±28.1 42.8±32.3	0.729	50.8±21.7 48.8±20.9	0.774	56.8±20.4 53.3±25.4	0.634	68.8±18.9 71.4±18.7	0.670	58.9±25.9 62.5±26.9	0.670	58.4±13.3 56.8±15.9	0.739
Co-morbidity	Yes No	66.3±20.2 53.8±29.9	0.103	64.3±23.1 66.8±18.7	0.684	48.8±28.3 42.3±30.1	0.464	49.2±22.8 51±20.7	0.777	50.8±24.2 59.7±19.3	0.175	66.3±21.7 72.3±15.9	0.284	65.8±26.4 55.4±25.2	0.187	58.7±15.1 57.3±13.4	0.739
Primary cause of CKD	Urologic Non-urologic	60.7±13.8 57.2±16.3	0.448	65.4±19.4 64.7±20.1	0.906	52.2±25.3 55.1±17.6	0.653	48.3±26.7 49.2±20.4	0.898	55.7±23.6 52.5±24.6	0.661	70.3±15.4 69.3±17.5	0.841	55.1±19.2 57.3±21.5	0.722	61.0±13.3 58.6±12.6	0.539

Abbreviations: AMKD: About my kidney disease; F/PI: Family and peer interaction; GF: General fatigue; PPA: Perceived physical appearance; TP: Treatment problems; SD: Standard deviation.

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Table 4. PedsQL™ 3.0 end stage renal disease module mean scores (parent-proxy) by characteristics

Variables		GF		AMKD		TP		F/PI		Worry		PPA		Communication		Total	
		Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P
Age	5-7 8-12 13-18	67±20.2 83.6±17.5 54.6±26.6	0.001	60.5±20.7 74.5±14.7 56.4±16.6	0.009	59.7±29 51.9±31.3 60±16.5	0.624	58.3±18.6 73.2±18.1 55±25.7	0.037	62.7±23.1 72.8±22.7 62±28	0.382	69.7±16.7 75.8±26.5 65.6±24.3	0.452	54.1±23.3 61.3±28.8 70.7±33.2	0.357	61.7±11.2 70.5±16.1 60.6±13.6	0.104
Sex	Male Female	70.8±25.9 65.6±18.3	0.517	65.2±19.8 64.4±12.4	0.886	58.6±24.9 46.9±32.4	0.259	64.2±24.2 60.4±9.7	0.479	68.2±26.5 59.9±12.8	0.394	74.1±24.4 56.3±12.4	0.007	63.±31.3 59.4±18.2	0.633	66.3±15.7 58.9±6.9	0.202
Residence	Rural Urban	62.8±21.2 75±26.1	0.102	58.7±15.6 69.7±19.4	0.049	55.9±25.4 56.9±27.6	0.897	61.8±26.3 64.7±19.3	0.671	71.8±20.6 62.9±27.2	0.239	66.7±23.1 74.1±24.1	0.308	52.4±28.1 70.2±28.3	0.042	61.5±15.1 67.7±14.1	0.165
Socioeconomic class	I-III4 IV-V	72±24.9 67.9±24.8	0.588	65.1±21.2 65±16.3	0.992	56.5±25.2 56.5±27.9	0.996	60.7±18.3 65.9±25.4	0.436	59.4±26.9 73.1±21.2	0.064	70.6±22.9 71.2±24.8	0.940	61.7±30.8 63.5±28.5	0.833	63.7±11.9 66.2±16.9	0.583
Family size	≤45 >4	66.9±28.5 71.6±22.3	0.538	64.7±20.7 65.2±17.5	0.929	55.5±32.6 57.1±22.5	0.858	65.2±23.2 62.5±22.1	0.699	55.8±31 73.3±17.6	0.045	75.4±24.2 68.2±23.4	0.319	75.9±27.7 54.6±27.7	0.016	65.6±16.8 64.7±13.7	0.830
Enrolled in school	Yes No	67.2±25.2 72±24.5	0.521	63.5±20.5 66.±17.1	0.627	56.3±27.1 56.7±26.5	0.951	63.8±25.5 63.3±19.8	0.951	59.5±30.7 72.5±17.2	0.100	67.5±26.8 73.6±20.9	0.391	66.3±(29.9 59.8±28.9	0.469	63.4±16.4 66.3±13.3	0.515
Family status	Parents together Parents separated	87.5±13.5 68.1±24.9	0.135	81.3±13.8 63.4±18.3	0.066	56.9±26.4 53.1±29.9	0.791	63.4±23.2 64.6±7.9	0.922	66.3±25.9 70.6±6.6	0.744	75.0±21.5 70.5±24.1	0.723	62.9±30.6 60±5.8	0.605	64.5±15.1 70.2±10.6	0.460
Mothers' age group	<40 ≥40	78.8±17 66.2±26.5	0.120	70±17 62.9±19	0.247	58.7±25.3 55.7±27.2	0.735	60.3±14.1 64.8±24.9	0.538	69.6±9.2 65.5±28.8	0.619	71.1±20.3 70.8±25.2	0.968	46.2±19.3 69.4±30.2	0.004	64.9±8.9 65.1±16.6	0.982
Mothers' education	≤High school ≥Higher secondary	67.7±21.9 72.3±27.8	0.537	63.6±18.9 66.7±18.5	0.585	53.1±25.3 60.4±27.7	0.362	59.1±21.7 68.7±22.3	0.150	66.2±21.8 66.2±28.3	0.892	66.3±22.1 76.2±24.9	0.166	53.3±25.3 73.3±30.3	0.020	61.4±14 69.1±14.7	0.083
Fathers' age group	<40 ≥40	78.1±14.8 67.5±26.5	0.113	71±16.1 63.3±19.1	0.253	60±26.3 55.5±26.7	0.643	65±11.7 63.1±24.6	0.734	68.5±9.1 66.2±27.7	0.674	68.3±20.3 71.7±24.8	0.699	52±16.5 65.7±31.5	0.076	66.1±8.5 64.7±16.2	0.791
Fathers' education level	≤High school ≥Higher secondary	60.4±24.7 73.3±24.1	0.122	59.7±17.4 66.9±18.8	0.249	51.6±25.7 58.3±26.8	0.453	53.4±26.2 67.2±19.8	0.068	65±22.2 67.3±25.9	0.783	69.4±24.4 71.4±23.7	0.803	52.5±26.5 66.4±29.7	0.162	58.8±14.9 67.2±14.2	0.091
Family history of renal disease	Yes No	65.6±11.9 70.3±25.6	0.723	58.8±17.5 65.6±18.7	0.485	62.5±28.4 55.9±26.5	0.641	64.6±23.9 63.4±22.4	0.922	75±12.4 65.9±25.6	0.489	64.6±17.1 71.5±24.3	0.581	40±16.8 64.9±29.4	0.105	61.6±10.6 65.4±15.1	0.628

Variables		GF		AMKD		TP		F/PI		Worry		PPA		Communication		Total	
		Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P
Time since the 1st diagnosis of CKD (m)	≤12 >12	71.4±28.8 69.6±24.2	0.857	75.7±26.2 63.1±16.5	0.098	43.8±25.5 58.9±26.2	0.166	66.7±20.4 62.9±22.8	0.689	50.4±33.5 69.7±22.0	0.185	72. 6±27.5 70.6±23.3	0.840	71.4±25.4 61.1±29.9	0.395	64.5±11.8 65.1±15.3	0.928
Time since 1st dialysis (m); placement	≤12 >12	76.7±26.1 67.6±24.1	0.295	71.4±20.1 62.9±17.8	0.196	54.5±25.8 57.2±26.9	0.778	62.8±27.7 63.7±20.7	0.914	65.6±29.8 67.1±23.4	0.864	75±32.5 69.6±20.5	0.613	60.5±28.9 63.4±29.8	0.777	66.6±18.9 64.5±13.4	0.681
Modality of renal replacement therapy	Peritoneal dialysis Hemodialysis	75.5±22.9 64.8±25.5	0.146	68.4±14.3 62.1±21.4	0.248	63.9±28.8 50±22.7	0.076	69.1±20.1 58.7±23.3	0.121	69.1±19.5 64.5±28.8	0.546	70.2±21.8 71.5±25.6	0.858	64.3±28.6 61.3±30.4	0.733	68.7±13.8 61.8±15.1	0.123
No. of medications	<5 ≥5	77.5±18.4 67.7±25.9	0.271	75.5±18.5 62.1±17.7	0.041	66.9±23.2 53.5±26.8	0.163	75.8±14.4 60±23	0.046	69.8±25.6 65.8±24.8	0.662	76.7±21.8 69.3±24.2	0.391	62±22.1 62.8±31.2	0.923	72±10.8 63±15.2	0.089
Hg level (g/dL)	<11 ≥11	72.1±21.2 68.9±26.2	0.701	66.5±18.8 64.4±18.6	0.735	63.9±21.5 53.5±27.9	0.234	69.2±17.8 61.1±23.7	0.278	71.2±15.3 64.8±27.6	0.438	71.1±17.8 70.8±25.9	0.962	50.3±19.6 67.7±31.2	0.033	66.4±9.2 64.4±16.6	0.702
No. of times hospitalized (past 6 months)	≤1 >1	73.4±22.1 62.1±28.8	0.156	67.5±18.4 59.6±18.3	0.194	58.9±29.2 51.3±18.9	0.382	68.5±21.8 52.4±19.7	0.022	70.6±23.7 58.1±25.6	0.116	74.2±21.2 63.7±27.9	0.171	60.8±28.2 66.8±32.3	0.532	67.7±14.8 59.1±13.3	0.070
Comorbidity	Yes No	66.9±27.3 72.3±22.6	0.474	63.6±19.9 66.2±17.6	0.641	56.3±25.6 56.8±27.5	0.951	57.1±22.3 68.7±21.2	0.083	53.7±28.6 77.2±14.8	0.002	65.8±26.6 75±20.7	0.2	68.3±31.8 58.2±26.8	0.257	61.6±14.5 67.7±14.6	0.170
Primary cause of CKD	Urologic Non-urologic	62.7±12.8 60.2±13.4	0.529	61.2±16.3 59.4±18.4	0.733	62.2±21.8 60.1±18.6	0.729	56.4±18.4 57.8±19.6	0.807	68.3±22.5 65.5±18.4	0.648	66.4±12.5 67.7±18.4	0.788	59.0±18.8 61.3±16.4	0.663	68.3±17.6 70.7±19.3	0.668

Abbreviations: AMKD: About my kidney disease; F/PI: Family and peer interaction; GF: General fatigue; PPA: perceived physical appearance; TP: Treatment problems; SD: Standard deviation.

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Table 5. Agreement between child and parent-reported mean pedsQL™ 3.0 end-stage renal disease scores

Domains	Intraclass Correlation Coefficient	95% CI
GF	0.793	0.551-0.896
AMKD	0.804	0.643-0.893
TP	0.714	0.451-0.848
F/PI	0.294	-0.178-0.591
Worry	0.653	0.339-0.814
PPA	0.570	0.213-0.765
Communication	0.916	0.847-0.953
Total	0.741	0.427-0.872

Abbreviations: AMKD: About my kidney disease; F/PI: Family and peer interaction; GF: General fatigue; PPA: Perceived physical appearance; TP: Treatment problems; SD: Standard deviation.

Internal consistency reliability

The Cronbach α coefficients of PedsQL™ 3.0 ESRD module total scale scores for child self-report and parent-proxy reports approached or exceeded the reliability criterion of 0.90 recommended for analyzing individual patient scores (Table 2). For child self-report scales, α values in five domains exceeded the minimum reliability standard of 0.70 required for group comparisons whereas, for parent proxy-report scales, four domains had α values above 0.7.

Parent-child agreement

The agreement between parent proxy-reported and child self-reported QOL is presented in Table 5. ICC for 4 of 7 domains was in good agreement range, while in the remaining domains, each had poor (family and peer interaction), moderate (PPA), and excellent (communication) agreements. The greatest overall agreement was found in the communication scale (ICC=0.916). The total scale scores also had good ICC between child and parent reports.

Discussion

Besides somatic treatment, the HRQOL has been recognized as one of the most essential patient care objectives in recent years. The present study is one of the very few studies to report data on HRQOL among Indian children with ESRD, using the PedsQL™ 3.0 ESRD module. It was conducted in a tertiary care center in northern India with a large referral base, hence, the results can be considered representative of a large subset of the population. Accordingly, children with CKD-5D had low QOL scores, with the worst scores seen in the TP domain based on both child self-report and parent-proxy report. The next most affected domains were F/PI (child self-report) and communication (parent proxy report). The only data (abstract form) available in Indian children with CKD (including CKD-5D) by Reddy et al. also showed similar results (mean PedsQL™ ESRD total score=57.2±13.2) with F/PI being the most negatively affected domain (39.9±18.2) [9]. Other studies from Singapore, Sub-Saharan Africa, Egypt, Korea and the UK have also shown comparable results (Table 2) [2, 7, 14-16]. However, the HRQOL of our study population was much worse than the study by Goldstein et al. in the US population [1, 17]. The difference could be attributed to differing inclusion criteria as our cohort included only dialysis patients while Goldstein et al. included transplant patients as well, who had better scores [1]. Other potential explanations for the inconsistent results include the stage of CKD, varying standards of care provided to these children in different countries, environmental differences, and the individual perception of QOL.

The presence of impaired QOL in children with CKD-5D could be explained by the fact that these patients experience numerous long-term and short-term complications that affect wellbeing, including frequent outpatient visits and hospitalizations, school absence, need to take multiple medications, dietary restrictions, painful medical procedures and restriction of activities which have behavioral and negative emotional outcomes [7]. This explains the greatest impact seen in the treatment problems domain in our study which includes questions, such as “difficulty remembering to take their medicines,” “not

liking how they feel after taking their medications," "difficulty drinking the amount of fluid they are supposed to" and so on.

The results of our study demonstrated significant variation in the AMKD scores among different age groups, with children aged 13-18 years reporting the worst and those between 8-12 years of age reporting the best QOL, both as per child and parent reports. F/PI was impacted maximally in children aged 5-7 years, according to the child report, and in children aged 13-18 years as per parent report. Likewise, age had a significant effect on the GF domain as well, with the lowest QOL in children aged 13-18 years as per parent report. Similarly, Neul et al. reported an inverse relation between patient age at enrolment and parent-proxy ESRD total as well as GF and AMKD domain scores in children with CKD stage 5 (dialysis, transplant) [18]. They also found a similar relation between age and PedsQL 4.0 generic core scale scores. Another study by Marciano et al. demonstrated that older age (age >10 years) was associated with lower QOL scores in almost all domains of the parents' report using PedsQL 4.0 generic core scales in children with CKD (conservatively managed, dialysis and transplant) [19]. On the contrary, in the study by Gerson et al. on children with mild to moderate CKD, older age was associated with higher PedsQL 4.0 generic core scale scores in the domains of physical, emotional, and social functioning, whereas, lower scores were seen in the school functioning domain [20].

The maximum impact on the QOL in the adolescent age group can be explained as adolescence is related to puberty, social and sexual identity, and peer interaction, so chronic illnesses like CKD could be a stigma that hampers social and cognitive function, independence, and self-esteem [21]. Children at this age should have good self-esteem and autonomy. Hence, CKD patients with physical limitations due to the disease or the complications would affect self-autonomy, which might have led to disappointment and finally low QOL [21]. The likely reason for impaired F/PI in 5 to 7-year-olds could be the vulnerability of these young children, the isolation from peers and family members associated with dialysis therapy thrice-weekly in-center HD or continuous ambulatory PD, and the overall difficulty in expressing themselves.

Parents of female participants reported lower QOL in the PPA domain, while no effect of gender was noted based on child reports. Similarly, Neul et al. reported gender to be significantly associated with ESRD total and PPA domain scores with female patients scoring lower than males based on child-report [18]. Another study by Marciano et al. showed female gender to be independently associated with a worse HRQOL using PedsQL 4.0 generic core scales based on patients' reports [19]. This finding suggests that female patients are more concerned about the negative effects of disease on their appearance than males. Moreover, this finding correlates with the previous adult and pediatric studies reporting lower QOL in female patients with various diseases and this effect is likely further exaggerated in CKD-5D patients [22]. In contrast, the only effect of gender noted by Park et al. was in the TP domain with girls having better scores than boys based on the child self-report PedsQL ESRD 3.0 module [2].

Children residing in rural areas had impaired QOL compared to urban children, especially total scores and in the domains of GF (child self-report) and AMKD (parent report). This is possibly due to inequitable health resource distribution and inadequate social support systems in rural areas. Regarding family status, children of separated/divorced parents reported worse QOL in the domains of AMKD and worry. However, no effect on QOL was observed based on parent reports. Similarly, children with both parents reported better social functioning and experienced a higher QOL than children from single-parent families in the study by Kiliś-Pstrusińska et al. [5]. This is because a higher sense of security, stability, and support from both parents leads to a child having higher self-esteem [5].

Maternal age had a significant effect on the QOL, with children of older mothers reporting impaired QOL in the AMKD domain, whereas, more communication difficulties were observed among children of younger mothers (both child self-report and parent proxy report). No effect of fathers age was seen on any domain. Similarly, Park et al. also noticed the effect of parental age on QOL, with children having younger fathers reporting better QOL than those with older fathers [2]. However, they did not find any effect on maternal age. It can be argued that since mothers are the primary caregivers in our region/society, maternal age has a definite impact on a child's perception of life.

Although we did not find any relationship between family size and child-reported QOL, parents of children belonging to smaller families noticed more worry issues in their children. Conversely, parents of children from larger families observed that their children had more problems in the communication domain. Another important finding was the effect of maternal education, children of less educated mothers had poorer commu-

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nication skills than those of mothers with higher education, according to child self-report and parent-proxy report. Likely, more educated mothers communicate better with their children, resulting in improved communication skills in these children. Moreover, these children had lower QOL in the GF domain. The father's lower education was also associated with impaired QOL in the GF domain.

Concerning the effect of dialysis modality, children who were on HD reported lower QOL in nearly all domains when compared to those on PD; however, the difference reached statistical significance only in the TP domain. Similarly, parents of children on HD tended to report lower QOL than the parents of children on PD (difference not statistically significant). These findings are in line with that of Park et al. who also reported better QOL in patients on PD in TP (child), AMKD, and worry (parent) domains than those undergoing HD [2]. Other studies have also reported similar findings [5, 15, 23, 24]. This could be because the patients on PD have greater autonomy with more advanced coping skills than those on HD. HD limits daily life activities to a greater extent, with a greater number of complications and a higher number of hospitalizations [5]. However, other authors have found no difference in QOL between HD and PD patients [8, 19, 25].

Parents reported lower QOL in the domains of AMKD and F/PI in children who were taking a greater number of medications. This finding possibly reflects that children on many medications are experiencing a greater severity of illness and or more illness-related complications, requiring more frequent dialysis and hospitalizations. If being on many medications were deemed to be inconvenient or a constant reminder of a child's chronic condition, one would expect the TP score to be affected by this variable as well. A similar effect of medication intake was observed on physical scores by McKenna et al. [8].

Also, parents noticed poorer communication skills in children having anemia than those without. More number of hospitalizations in the previous 6 months resulted in lower QOL in F/PI based on parent reports. We did not find any effect on school enrolment; however, only 7 children were attending school. This problem of low attendance needs to be addressed. Children and adolescents with chronic conditions, as well as their families, often occupy their time and thoughts on treatment, neglecting other aspects of their lives. This often causes school dropout, frequent absences, reduced interest, and lack of motivation to learn. There is a need for schools to know and participate in what happens to their students so that they can provide comfort and act as another support network [26].

No effect of socioeconomic status, duration of CKD, or time since initiation of dialysis was noted. Previous studies have revealed variable findings. Similar to our study, Kiliś-Pstrusińska et al. did not find any effect of the duration of nephrological care on HRQOL, suggesting that although early nephrological care improves the clinical condition of CKD patients, it is not sufficient to minimize the psychosocial aspects resulting from kidney disease [5]. On the other hand, studies have reported low to better scores in children with increasing duration of CKD [2, 9, 20, 21].

Meanwhile, the children rated their QOL lower than their parents which is contrary to the findings of other authors [5, 8, 18, 27]. A lack of concordance between children and caregivers has been reported in healthy and chronically ill children [28]. As parent and child data may reflect individual standards, even when evaluating the same subject, this discrepancy is not surprising. A child's perceptions of health status might mirror their parent's only when they mature cognitively to the level of their parent [8]. A systematic review concluded that convergence of rating is better on the subscales related to directly observable functioning and with no emphasis on subjective qualities [29]. therefore, it reaffirms the importance of assessing both self and proxy reports.

Our finding that children with CKD-5D and their parents showed moderate to excellent agreement on ICC, is better than most of the previous reports [1, 7, 8]. It has been suggested that the levels of agreement can be affected by the child's age, the domains investigated, and the parents' QOL [30]. Taken together, the evidence suggests that evaluating both children's and parent's perspectives should be the standard in clinical studies for children with CKD-5D because their different perspectives potentially provide unique information about treatment outcomes [1].

The strengths of the present study include the use of the Hindi version of the disease-specific module, a modest sample size, and the use of both child and parent-proxy reports. Also, since our center caters to a large population of north India with a large referral base, the results are representative of a large population.

Conclusion

CKD stage 5D exerts a significant impact on the HRQOL of affected children and presents numerous challenges that affect various aspects of a child's well-being. Therefore, the comprehensive management of CKD-5D in children should address not only the physical aspects but also the psychological and social dimensions, aiming to enhance their HRQOL and promote holistic well-being.

Study limitations

This study faced some limitations, including its single-center, cross-sectional design, and non-inclusion of transplant patients. Also, there is a lack of qualitative data, which precludes an in-depth analysis of children's experiences of living with CKD-5D. Further multicentric studies with longitudinal design would allow the evaluation of changes in morbidity and QOL over time.

Ethical Considerations

Compliance with ethical guidelines

This study was approved by the Ethics Committee of Sir Ganga Ram Hospital (Code: No-EC/01/18/1317). All procedures performed in the current study involving human participants were following the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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Authors' contributions

Data collection, analysis and final approval: All authors; Writing the original draft: Rufaida Mazahir.

Conflict of interest

The authors declared no conflict of interest.

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