

Quality of life in children and adolescents with chronic kidney disease: a comparative study between different disease stages and treatment modalities

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This study aimed to compare the quality of life of children and adolescents in various stages of their chronic kidney disease (CKD) who were managed with different treatment modalities to that of children and adolescents without any chronic disease. The study included 18 renal transplant and 21 dialysis patients (8 on hemodialysis, 13 on peritoneal dialysis) and 16 patients who did not yet require renal replacement therapy. The control group consisted of 37 children without any chronic disease. Psychosocial Health Summary scores, Physical Health Summary scores, and Total Scale scores of Pediatric Quality of Life Inventory scores were estimated for the groups. CKD patients had lower scores in all scales of Pediatric Quality of Life Inventory than the control group. There were no differences in self-reported scores on the Pediatric Quality of Life scale scores between treatment groups; however, parents of the transplant patients had reported higher (more favorable) Physical Health Summary scores than those of the dialysis patients. Reports of parents and their children differed only in Physical Health Summary scores in the dialysis group; self-reports of the children were more favorable. These findings show that children and adolescents with CKD experience impaired quality of life on the physical and psychosocial functioning domains in comparison with healthy controls. The study findings implicate the need for further studies to investigate the quality of life in CKD patients at different stages as well as the perceptual differences between pediatric and adolescent CKD patients and caregiver proxy-reports about their quality of life.

Key words: chronic kidney disease, renal failure, quality of life, transplant, dialysis, non-dialysis-CKD treatment.

Chronic kidney disease (CKD) is an important health problem for adult as well as pediatric and adolescent populations. Apart from its life-threatening aspect, because of its impact on quality of life (QOL) of the patients, investigation of the changes occurring in QOL has gained in importance.

Today, opinions suggesting that frequently used conventional concepts such as morbidity, mortality, and life expectancy for the

measurement of public health are not sufficient to assess state of health and well-being are gaining importance. In place of these concepts, measurement of QOL was proposed as a more correct approach for the evaluation of health care services¹. Health-related quality of life (HQOL) focuses only on the well-being of an individual, and refers to an individual's satisfaction with his/her own present health state. When evaluated from this perspective, HQOL is directly linked with the individual's

perception of him/herself and all effects of his/her disease and the treatments applied.

Assessment of QOL of children and adolescents diagnosed with CKD is a relatively new subject that has recently gained in popularity^{2,3}. The most important reasons for this increased popularity have been associated with advances in therapeutic approaches, and attempts to use HQOL assessments as important clinical criteria^{4,5}.

When the literature data are reviewed, it is revealed that various studies have provided numerous data about adversely affected QOL parameters in adult populations, especially those with end-stage kidney diseases^{6,7}.

Though many studies have been conducted in pediatric and adolescent populations, a limited number of investigations are related to comparisons between treatment groups in terms of QOL of the patients. Comparisons of the effects of different treatment alternatives on QOL of the patients with CKD, which is an important health problem with its higher incidence and clinical severity, gain importance in the determination of the areas for intervention and the best treatment alternatives. Since more children with CKD are reaching adult age, the best care in the pediatric nephrology units requires attention to the psychosocial and developmental factors with the intention to support the successful transition of pediatric patients to adulthood.

This study aimed to make comparisons in terms of QOL between 1) the control group and children and adolescent patients with CKD 2) who had undergone renal transplantation, 3) were included in the dialysis program, or 4) were at stage III or IV and did not yet require renal replacement therapy (non-dialysis (ND) - CKD patients).

Material and Methods

The study enrolled 55 children and adolescent patients followed with the diagnosis of CKD in the Pediatric Nephrology Unit of Hacettepe University Faculty of Medicine. Patients with CKD with any concomitant chronic diseases were excluded.

The control group consisted of age- and gender-matched volunteers who were referred to outpatient clinics of Hacettepe University

for any other reason without any evidence of chronic disease. The investigation was approved by Ankara 3rd Ethics Committee of Clinical Investigations, and was designed as a controlled, cross-sectional study.

Diagnostic Instruments

Pediatric Quality of Life Inventory (PedsQL)

The PedsQL is a scale developed by Varni et al.⁸ in order to measure HQOL of children and adolescents aged 2-18 years. The PedsQL scale consists of 23 items. Scoring was performed for three domains; firstly, total scale score (TSS), then Physical Health Summary Scores (PHSS), and Psychosocial Health Summary Scores (PSHSS), which consist of items evaluating emotional, social, and school functioning, are calculated. As a consequence, the higher total PedsQL scale scores, the more satisfactory the perceived HQOL. Validation and reliability of the scale were performed by Memik et al.⁹.

Statistical Evaluation

Statistical analysis of our study was performed using the Statistical Package for the Social Sciences (SPSS) 15.0 program. Normality of the distribution of data was evaluated with visual (histograms etc.) and statistical (Kolmogorov-Smirnov and Shapiro-Wilks) tests. Homogeneity of variance was evaluated with Levene's test. For the comparison of more than two independent groups with normally distributed data and homogeneous variances, one-way ANOVA, and for post-hoc comparisons, Tukey test, were used. In cases where homogeneity of variance was not required, Welch ANOVA test was used. For the comparison of more than two independent groups with non-normal distribution, Kruskal-Wallis test was utilized. For pairwise comparisons among four groups, the Mann-Whitney U test with Bonferroni correction was employed, and $p < 0.008$ was accepted as the level of significance. In the comparison of two dependent groups, dependent groups-t test was used for data with normal distribution, and for data with non-normal distribution, Wilcoxon test was employed. For the evaluation of categorical variables, chi-square test was used. A value of $p < 0.05$ was accepted as the level of significance.

Results

Eighteen renal transplant, 21 dialysis (8

Table I. Demographic Features and PedsQL scores

	age (month)	Mother's age	Father's age	PedsQL TSS(m)	PedsQL PHSS(m)	PedsQL PSHSS(m)	PedsQL TSS(c)	PedsQL PHSS(c)	PedsQL PSHSS(c)
Control (n=37)	Mean	40.4	42.7	94.2	96.3	93.2	93.5	94.4	93.2
	SD	27.4	3.9	3.6	3.9	4.7	3.1	3.4	3.7
	Median	153.0	40.0	42.0	94.6	96.9	95.0	94.6	93.3
	Min	104.0	33.0	35.0	86.0	87.5	80.0	86.7	83.3
	Max	192.0	49.0	54.0	100.0	100.0	100.0	100.0	100.0
Transplant (n=18)	Mean	161.7	39.2	44.3	71.2	70.1	74.2	73.6	74.5
	SD	27.2	5.5	6.6	12.8	16.0	14.7	13.8	15.3
	Median	160.0	38.5	44.0	72.3	71.9	74.2	77.2	76.7
	Min	120.0	31.0	34.0	50.0	34.4	41.7	47.8	45.0
	Max	200.0	50.0	61.0	90.2	93.8	88.3	91.3	100.0
Dialysis (n=21)	Mean	162.2	38.0	42.2	57.9	51.2	66.1	62.1	68.3
	SD	28.8	7.1	6.2	17.1	19.8	18.5	16.9	16.1
	Median	156.0	38.0	42.0	64.1	53.1	65.0	70.7	76.7
	Min	120.0	26.0	33.0	25.0	15.6	26.7	35.9	40.0
	Max	216.0	50.0	55.0	84.8	81.3	90.0	87.0	88.3
ND-CKD (n=16)	Mean	151.7	39.9	43.5	68.5	63.1	69.4	65.4	69.7
	SD	35.7	6.2	6.2	13.7	15.9	14.3	15.5	15.7
	Median	156.0	40.0	44.0	65.2	62.5	70.0	72.8	71.7
	Min	96.0	28.0	29.0	47.8	34.4	40.0	34.8	40.0
	Max	204.0	51.0	56.0	88.0	87.5	93.3	88.0	90.0
p	0.41+	0.52*	0.65+	<0.001*	<0.001**	<0.001**	<0.001**	<0.001**	<0.001**

+ANOVA *Welch ANOVA ** Kruskal-Wallis analysis
PedsQL: Pediatric Quality of Life Inventory. TSS: Total Scale Score. PHSS: Physical Health Summary Score. PSHSS: Psychosocial Health Summary Score. ND-CKD: Non-dialysis chronic kidney disease. m: Mothers. c: Children.

Table II. Pairwise Comparisons of PedsQL Scores

	Control vs Transplant	Control vs Dialysis	Control vs ND-CKD	Transplant vs Dialysis	Transplant vs ND-CKD	Dialysis vs ND-CKD
TSS(m)***	<0.001*	<0.001*	<0.001*	0.006*	0.964	0.040
PHSS(m)**	<0.001*	<0.001*	<0.001*	0.001*	0.155	0.077
PSHSS(m)**	<0.001*	<0.001*	<0.001*	0.148	0.980	0.213
TSS(c)**	<0.001*	<0.001*	<0.001*	0.088	0.290	0.820
PHSS(c)**	<0.001*	<0.001*	<0.001*	0.125	0.570	0.595
PSHSS(c)**	<0.001*	<0.001*	<0.001*	0.234	0.380	0.660

*Statistically significant **Mann-Whitney U test ***Tukey test
 TSS: Total Scale Score. PHSS: Physical Health Summary Score. PSHSS: Psychosocial Health Summary Score. NK-CKD: Non-dialysis chronic kidney disease. m: Mothers. c: Children.

hemodialysis, 13 peritoneal dialysis), 16 ND-CKD (at stage III-IV), and 37 control patients were included in the study. The 55 patients with CKD included 33 male (60%) and 22 female (40%) cases, while the 37 control subjects included 19 male (51.4%) and 18 female (48.6%) patients.

No statistically significant intergroup differences could be detected with respect to gender. Mean ages of the control, transplant, dialysis, and ND-CKD groups were 151.4±27.4, 161.7±27.2, 162.2±28.8, and 151.7±35.7 months, respectively, and no statistically significant difference was observed between the control and patient groups (p=0.41). Mean ages and educational levels of the parents of the children in the control and patient groups are shown in Table I. There was no statistically significant difference between groups (p=0.52, p=0.65).

A statistically significant difference was observed between the patient and control groups in all scale scores of TSS(mother [m]), PHSS(m), PSHSS(m), TSS(child [c]), PHSS(c) and PSHSS(c) (Table I, p<0.001). Pairwise comparisons between groups and p values are shown in Table II. Comparisons between transplant and ND-CKD groups as for all scale scores failed to demonstrate any statistically significant intergroup differences. Similarly, pairwise comparisons between the transplant and dialysis groups did not reveal any significant differences in PSHSS(m), TSS(c), PHSS(c), and PSHSS(c) scale scores (Table II).

On the PedsQL TSS, mothers of children in the CKD group rated their children more unfavorably than their children’s self-reports,

with a statistically significant difference in the dialysis group (p=0.023) (Fig. 1). There was no statistically significant difference between the transplant and ND-CKD groups in the PedsQL scores reported by mothers and children. However, only in the dialysis group, a statistically significant difference was observed between mothers’ PHSS report (mean: 51.2, SD: 19.8) and children’s self-reported PHSS (mean: 62.1, SD: 20.9) scores (p=0.029). In the control group, mothers’ PHSS scores (mean: 96.3, SD: 3.9) were significantly higher than their children’s self-reported PHSS scores (mean: 94.4, SD: 3.4) (p=0.009).

Discussion

In this study, a brief PedsQL scale based on the World Health Organization’s (WHO’s) definition of health, which also complied with

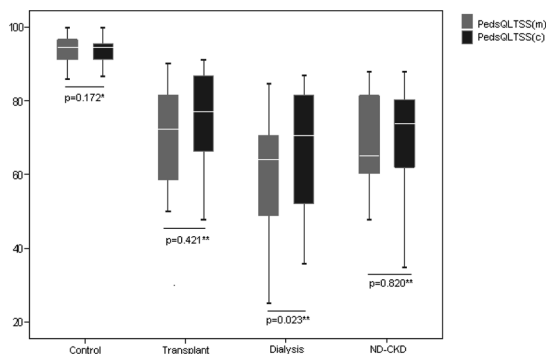


Fig. 1. Comparisons of PedsQLTSS(m) and PedsQLTSS(c) Scores

*Paired sample-t test **Wilcoxon test
 PedsQLTSS(m): Pediatric Quality of Life Inventory Total Scale (mothers). PedsQLTSS(c): Pediatric Quality of Life Inventory Total Scale (children). NK-CKD: Non-dialysis chronic kidney disease. m: Mothers. c: Children.

the developmental process of children and adolescents, was used. Although an integrated additional module of this scale for patients with end-stage renal failure is available¹⁰, lack of its validated Turkish version precluded its use in this study. However, in the literature, a CKD-specific module is not considered adequate in assessments of end-stage renal failure, and the global form of the scale is accepted as a valid and reliable tool^{5,10}.

The most important finding of this study was the detection of lower scores in all dimensions of PedsQL in the CKD group compared to healthy controls. This outcome of our study appears to be relatively supported by other literature data. Excluding some investigations performed after transplantation¹¹ in patients with end-stage renal disease and in children and adolescents diagnosed as CKD without regarding stage of the disease, QOL of the patients was found to be deteriorated when compared with healthy controls as evaluated by global and disease-specific assessments¹²⁻¹⁵. In addition, this result was confirmed by both data derived from reports of the parents and children's self-ratings independent of the effect of measurement. Differences between the assessments of parents and children's self-ratings have been noted in the literature. In the present study, in the CKD group, mothers rated QOL of their children with lower total scale and physical health summary scores when compared with the self-reports of their children. This difference was observed at the statistically significant level only in the dialysis group; in the transplantation and ND-CKD groups, the reports of mothers and the children's self-reports did not differ. Similarly, in the literature, in the CKD group, and especially in the dialysis group, mothers have rated their children more unfavorably than the children themselves¹⁶. Because of their pessimistic psychological health state and the invasive interventional nature of the dialysis, it is possible that mothers would rate their children more adversely. It was thought that mothers underestimated the physical functioning of their children in the dialysis group related to their own psychological state. However, it should be considered that differences between the mothers' reports and the children's self-reports can be explained by the different perceptions of the child and also by the defense mechanisms used by children in

the fight against their disease¹⁷. Indeed, denial and avoidance behaviors have been reported as the most frequently used defense mechanisms by children with chronic renal failure.

Many studies performed in adults have demonstrated improvements in many domains of QOL with adequate treatment¹⁸. Especially renal transplantation is the predominantly preferred treatment modality because of the resultant improvement in QOL. In the pediatric literature, controversial outcomes have been reported in comparative studies of treatment groups. However, many of these studies also found relatively improved QOL scores in compliance with the reports of the mothers of transplant-recipient CKD patients when compared with the assessments of the mothers of CKD patients undergoing dialysis therapy^{14,20-23}. In the present study, no intergroup differences between disease stages and treatment modalities, in all domains of PedsQL as evaluated by self-reports, were found, while in the reports of the mothers, significantly higher physical HQOL scores were observed in the transplantation group when compared with the dialysis group. Similarly, Goldstein et al.¹⁹ suggested that parents of children with end-stage renal disease had observed a positive impact of renal transplantation on the majority of HQOL inventory domains compared to dialysis, whereas children's self-report had generally demonstrated non-significant small effect differences in favor of renal transplantation. In the study performed by McKenna et al.¹⁶, who evaluated PedsQL in the end-stage renal disease group as well as in the ND-CKD group, which was also evaluated in the present study, no significant difference was found between disease stages and treatment modalities based on the self-reports. McKenna et al.¹⁶ mentioned that caregivers had underrated their children in almost all categories when compared with the children's self-reports, and also, in contrast to the children's self-reports, caregivers had assigned the lowest scores to children on dialysis. Similarly, in another study, differences between child self and parent proxy reports in the end-stage renal disease module scores of the PedsQL inventory were reported in favor of child self-reports²¹. In that study, no significant differences were found in total QOL scores allocated by children who had undergone

peritoneal dialysis or transplantation²¹. When studies that observed differences between the QOL scores of dialysis and transplant patients^{12,24} were evaluated, similar to the present study, physical health domain was the main area of difference. It was suggested that rehabilitation of physical health may improve the QOL perceptions in the dialysis group.

A scarce number of studies have investigated QOL of children and adolescents followed with the diagnosis of CKD without requirement for treatment modalities such as dialysis or transplantation to maintain their lives^{13,16,25}. Therefore, limited information was found concerning patients in phases before end-stage renal failure. In the present study, no significant difference was found between the ND-CKD, organ transplantation, and dialysis groups with respect to PedsQL scores. A larger scale prospective cohort study evaluated the relationship between the severity of renal failure and HQOL, and no correlation between QOL and the stage of organ failure could be found¹³. This finding suggested that interventions performed to improve QOL in the early stage of CKD might be of critical importance.

The major limitation of this study results from its cross-sectional design. In addition, the scarce number of children and adolescents diagnosed as CKD is another limitation of the study. In addition, because a limited number of children and adolescents diagnosed as CKD were enrolled in our investigation, it was not possible to make a concluding remark about the predictors of QOL such as duration of

dialysis, time passed after transplantation, and previous history of dialysis. Since the main objective of the study was not related to the factors determining the QOL of CKD patients, further studies are needed on this issue. Lack of any validated Turkish version of the QOL scale prevented usage of disease-specific assessment tools in this study. Utilization of disease-specific instruments will be more useful for the evaluation of treatment-related variables.

As the most important finding of the present study, QOL scores of children and adolescents diagnosed as CKD were lower than those of the control group. In addition, as another important finding, especially mothers whose children were under dialysis therapy rated QOL of their children more unfavorably when compared with the self-reports of the children. Children also did not share the perception of their mothers indicating that the physical health state of transplant recipients is better than that of those under dialysis therapy. In the healthy control and chronic disease groups, differences in assessments on common issues by the patients in self-reports and by health care providers have been demonstrated in relevant investigations^{26,27}. In the control group, perceptions of the mothers about the physical health state of their children were more favorable when compared with self-reports of their children. These results implicate the need for further studies to investigate the QOL in CKD patients at different stages as well as the perceptual differences between pediatric and adolescent CKD patients and caregiver proxy-reports about QOL.

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