

Health-related quality of life of pediatric renal transplant recipients and their parents: the role of associated factors and clinical counseling

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Background/aim: This study evaluates the health-related quality of life (HRQoL) of pediatric renal transplant recipients and their parents and investigates the effects of clinical, socioeconomic, and psychological factors as well as continuous counseling on the HRQoL.

Materials and methods: Patients aged 8–17 years (mean: 14.9 ± 2.9) were enrolled. Clinical and demographic data were noted. The Beck Depression Inventory (BDI), Rosenberg Self-Esteem Scale (RSES), and Turkish version of the Kinder Lebensqualität Fragebogen (KINDL) questionnaire for children and the BDI, RSES, parent-proxy version of KINDL, and Short-Form 36 (SF-36) for parents were applied (step 1). Following a 1-year counseling program, the tests were repeated (step 2).

Results: Child-self and parent-proxy KINDL scores were optimal with no difference between periods (for child-self and parent-proxy scores, $P > 0.05$). Parent SF-36 scores indicated optimal results. Parent RSES scores decreased in step 2 ($P < 0.05$). The BDI scores were higher in parents than children in both periods ($P < 0.05$ for step 1 and $P < 0.01$ for step 2). Higher creatinine levels, lower monthly income, and urological comorbidities modified the HRQoL negatively in step 1.

Conclusion: Continuous education with psychosocial counseling carries importance in improving HRQoL in the posttransplant period.

Key words: Renal transplantation, health-related quality of life, children, counseling

1. Introduction

As advances in immunosuppressive therapies and patient management have markedly improved allograft survival in children with renal transplantation (RTx), currently attention is being paid to their psychosocial adjustment and quality of life (QoL) (1–3). Studies evaluating the QoL of pediatric RTx patients and their caregivers mainly stated good long-term outcomes, whereas opposite results were reported in some others (1–11).

Nonadherence to treatment is a major issue especially in adolescents with RTx (12), which causes subtherapeutic immunosuppression, a leading cause of allograft rejection and graft loss. As it is indirectly associated with decreased QoL, patient education and awareness is considered pivotal in improving adherence (13).

Elucidating pre- and post-RTx factors that influence health-related QoL (HRQoL) is an important topic in developing interventions to improve HRQoL (14). In this prospective study, we aimed to determine the HRQoL and investigate the potential effects of clinical, socioeconomic, and psychological factors in children and adolescents with

RTx and their parents. Finally, we assessed whether the application of a continuous counseling and educational program modified these scores in a positive manner.

2. Materials and methods:

2.1. Participants

Twelve RTx patients (transplanted at least 6 months before the start of the study) attending the Gazi University Department of Pediatric Nephrology in 2009 and one of their parents were enrolled. Clinical and demographic data were recorded. Written consent and ethical approval were obtained.

2.2. Measures

At the onset (step 1), the Beck Depression Inventory (BDI), Rosenberg Self-Esteem Scale (RSES), and Turkish version of the Kinder Lebensqualität Fragebogen (KINDL) questionnaire for children and the BDI, RSES, parent-proxy version of KINDL, and Short-Form 36 (SF-36) for parents were applied by a senior pediatric nephrology fellow and a social worker.

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The BDI is used to screen depression and higher scores correlate with depression. The Turkish version was validated by Hisli (15–17). Self-esteem was assessed by the RSES. The Turkish version was developed by Çuhadaroğlu. Higher total scores point out low levels of self-esteem (18). The Turkish version of the KINDL questionnaire for children and a proxy version for parents were used to measure QoL. The self-report consists of six subscales and higher scores indicate better QoL (11,19). The SF-36 (a 36-item measure) is used to evaluate HRQoL in adults. A higher SF-36 domain score shows better HRQoL. Physical health summary (PHS) scores and mental health summary (MHS) scores are calculated (20).

2.3. Counseling program

After performing initial tests (step 1), a counseling and educational program was started. First, a slide-show about RTx including complications (infections, graft rejection/loss), medications (protocols, side effects), and daily life after RTx (sportive activities, nutrition) was presented to the study group. Information on their current status was then given, their questions were answered, and psychological counseling/support was provided in 2–4 weekly control visits. After 1 year, tests were repeated.

Results of both periods were compared and the effects of education on the scores were analyzed (step 2).

2.4. Statistical analysis

Continuous variables were given as mean \pm SD or median and compared using the Mann–Whitney U test. Categorical variables were summarized as percentages and compared using the chi-square test. Pearson correlation analysis was used to correlate between parameters. Analyses were performed with SPSS 15.0 (SPSS Inc., Chicago, IL, USA). Statistical significance was set at $P < 0.05$.

3. Results

3.1. Clinical data

Mean age was 14.9 ± 2.9 years. Mean height had significantly increased in step 2 ($P < 0.01$). Mean number of medications significantly decreased ($P < 0.01$) and creatinine levels were reduced in step 2 without statistical significance ($P > 0.05$). Two patients with coexisting neurogenic bladder (16.7%) received clean intermittent catheterization (Table 1).

3.2. Demographic findings

The mothers were mostly housewives ($n = 11$, 91.6%) and fathers were mostly workers ($n = 7$, 58.3%). Monthly

Table 1. Clinical data of the study group.

Descriptive variables	Step 1 n (%)	Step 2 n (%)	P
Sex (male / female)	8 (66.7) / 4 (33.3)		
Age (years)	14.9 ± 2.9 (8–17)	16.1 ± 2.9 (9–18)	
Height (cm)	148.5 ± 16.8	153.7 ± 14.8	<0.01
Body mass index	18.6 ± 2.8	19.6 ± 2.5	>0.05
Age at CKD diagnosis (years)	6.4 ± 3.4		
Preemptive RTx (yes)	2 (16.7)		
RTx (deceased / living related donor)	3 (25.0) / 9 (75.0)		<0.01
Living related donor (mother / father / other)	7 (77.8) / 1 (11.1) / 1 (11.1)		
Post-RTx duration (years)	3.2 ± 2.3	4.4 ± 2.4	<0.01
Number of medications	6.8 ± 1.7	4.8 ± 2.2	<0.01
Creatinine level (mg/dL)	0.92 (0.65–3.72)	0.86 (0.63–4.30)	>0.05
Glomerular filtration rate	85.2 (23.2–112.6)	97.5 (20.3–139.6)	>0.05
Visual-motor function disorders (yes)	1 (8.3)	1 (8.3)	
Neurogenic bladder (yes)	2 (16.7)	2 (16.7)	
Clean intermittent catheterization (yes)	2 (16.7)	2 (16.7)	

CKD: Chronic kidney disease; RTx: renal transplantation.

income was around the minimum wage level in half of the families.

3.3. Assessment of HRQoL

3.3.1. Children

KINDL tests indicated optimal HRQoL in both periods and the scores were similar in step 1 and step 2 ($P > 0.05$). RSES scores decreased in step 2 without statistical significance ($P > 0.05$). BDI scores were normal in both periods ($P > 0.05$, Table 2).

3.3.2. Parents

The parents' perception of their children's HRQoL was optimal and similar ($P > 0.05$) in both periods (by parent-proxy KINDL). Parent RSES scores significantly declined in step 2 ($P < 0.05$). Despite normal ranges, BDI scores slightly increased in step 2 ($P > 0.05$). SF-36 scores were optimal and similar in both periods, as well ($P > 0.05$, Table 3).

3.3.3. Comparison between children and parents

Child-self and parent-proxy KINDL scores were similar in both periods ($P > 0.05$ for both). No difference was present in the RSES scores of the two groups in both steps 1 and 2 ($P > 0.05$ for both). BDI scores of parents were significantly higher than those of children in step 1 ($P < 0.05$) with a more prominent difference in step 2 ($P < 0.01$).

3.3.4. Correlations

Patients with coexisting urological problems had higher RSES scores only in step 1 ($P < 0.05$). Their parents' BDI scores were also significantly higher than the other parents

in only step 1, as well ($P < 0.05$). Moreover, a positive correlation was present between creatinine levels and RSES scores of the children only in step 1 ($r = 0.668$, $P < 0.05$). Finally, parents with lower monthly income had higher BDI scores in only step 1 ($P < 0.05$).

4. Discussion

In our study, the children's perception of HRQoL was optimal and BDI scores were low in both periods. Therefore, we conclude that children felt themselves to be better after RTx compared to a troublesome pre-RTx chronic kidney disease period. As RSES scores mildly lowered in step 2, they probably had better self-esteem as the post-RTx duration continued.

The parents rated themselves to have optimal HRQoL in both periods according to the SF-36. Their RSES scores also significantly decreased in step 2, indicating an improvement in self-esteem (probably from handling the problems of their children). On the other hand, despite normal ranges in both periods, the parent BDI scores were slightly elevated in step 2. Their scores were also higher than those of children with a more prominent difference in step 2. Having a child with RTx can cause symptoms in the caregivers such as emotional dysfunction and depression (21). Similarly, in our study the parents' tendency to depression was apparent despite elevated self-esteem, probably secondary to challenges like taking on all the responsibilities of their children and fear of losing the graft.

Table 2. HRQoL tests of the patients.

Scales	Step 1			Step 2			P
	Mean ± SD	Median	(IQR)	Mean ± SD	Median	(IQR)	
KINDL (child-self)							
Physical well-being	4.23 ± 0.84	4.38	(4.00 – 4.94)	4.19 ± 0.99	4.63	(3.63 – 5.00)	>0.05
Emotional well-being	4.10 ± 0.85	4.13	(3.75 – 4.94)	3.85 ± 1.01	4.00	(3.00 – 4.69)	>0.05
Self-esteem	3.17 ± 1.32	3.50	(1.88 – 4.38)	3.40 ± 1.05	3.63	(2.94 – 4.00)	>0.05
Family	4.08 ± 0.60	4.25	(3.56 – 4.50)	4.08 ± 0.85	4.38	(3.56 – 4.88)	>0.05
Friends	4.19 ± 0.66	4.38	(3.63 – 4.69)	3.90 ± 0.88	4.00	(3.00 – 4.50)	>0.05
School	3.50 ± 0.89	3.63	(2.50 – 4.19)	3.65 ± 0.67	3.50	(3.25 – 4.00)	>0.05
Disease perception	3.43 ± 0.70	3.17	(3.00 – 4.00)	3.10 ± 0.92	3.42	(2.04 – 3.79)	>0.05
Total	3.90 ± 0.64	4.10	(3.53 – 4.30)	3.86 ± 0.70	4.13	(3.06 – 4.36)	>0.05
RSES	0.62 ± 0.67	0.50	(0.00 – 1.35)	0.28 ± 0.35	0.09	(0.00 – 0.62)	>0.05
BDI	4.00 ± 3.69	4.00	(1.25 – 5.50)	4.17 ± 3.24	4.00	(1.25 – 6.75)	>0.05

KINDL: Kinder Lebensqualität Fragebogen; RSES: Rosenberg Self-Esteem Scale; BDI: Beck Depression Inventory.

Table 3. HRQoL tests of the parents.

Scales	Step 1			Step 2			P
	Mean ± SD	Median	(IQR)	Mean ± SD	Median	(IQR)	
KINDL (parent-proxy)							
Physical well-being	4.04 ± 0.84	4.25	(3.19 – 4.75)	3.98 ± 1.17	4.50	(2.94 – 5.00)	>0.05
Emotional well-being	4.04 ± 0.67	4.00	(3.50 – 4.69)	3.71 ± 1.05	4.00	(2.75 – 4.63)	>0.05
Self-esteem	3.58 ± 1.30	4.00	(2.63 – 4.81)	3.98 ± 0.76	3.63	(3.31 – 4.88)	>0.05
Family	4.23 ± 0.64	4.50	(3.56 – 4.75)	4.06 ± 0.72	4.13	(3.38 – 4.69)	>0.05
Friends	4.02 ± 1.07	4.25	(3.38 – 4.94)	3.56 ± 1.07	3.75	(2.75 – 4.38)	>0.05
School	3.69 ± 0.98	3.50	(2.81 – 4.69)	3.54 ± 0.76	3.63	(2.81 – 4.13)	>0.05
Disease perception	3.53 ± 0.86	3.33	(2.75 – 4.42)	3.43 ± 0.86	3.50	(2.58 – 4.25)	>0.05
Total	3.93 ± 0.60	4.13	(3.40 – 4.46)	3.81 ± 0.70	3.85	(3.43 – 4.52)	>0.05
RSES	0.60 ± 0.42	0.58	(0.27 – 0.94)	0.14 ± 0.29	0.00	(0.00 – 0.13)	<0.05
BDI	9.58 ± 5.57	9.50	(5.00 – 13.75)	11.83 ± 9.19	8.00	(6.25 – 19.25)	>0.05
SF-36							
Physical function	85.42 ± 18.76	95.00	(70.00 – 100.00)	65.42 ± 30.11	65.00	(50.00 – 96.25)	>0.05
Physical role	56.25 ± 47.82	75.00	(0.00 – 100.00)	56.25 ± 44.11	62.50	(6.25 – 100.00)	>0.05
Pain	65.33 ± 30.33	73.00	(36.00 – 96.00)	61.92 ± 30.41	63.00	(38.50 – 84.00)	>0.05
General health	54.33 ± 21.76	55.00	(34.00 – 65.75)	57.92 ± 26.57	52.50	(45.00 – 85.75)	>0.05
Energy/fatigue	56.25 ± 29.40	60.00	(31.25 – 78.75)	54.58 ± 23.98	57.50	(50.00 – 73.75)	>0.05
Social function	78.13 ± 27.76	87.50	(65.63 – 100.00)	76.04 ± 24.11	87.50	(53.13 – 96.88)	>0.05
Emotional role	66.67 ± 37.61	83.33	(33.33 – 100.00)	44.44 ± 32.82	50.00	(8.33 – 66.67)	>0.05
Emotional well-being	69.33 ± 14.10	72.00	(54.00 – 80.00)	70.33 ± 18.87	74.00	(54.00 – 84.00)	>0.05
PHS	45.47 ± 11.06	49.09	(33.16 – 53.92)	42.90 ± 12.52	41.95	(29.13 – 55.52)	>0.05
MHS	46.78 ± 7.39	48.23	(39.71 – 53.98)	45.73 ± 8.51	49.58	(39.28 – 51.66)	>0.05

KINDL: Kinder Lebensqualität Fragebogen; RSES: Rosenberg Self-Esteem Scale; BDI: Beck Depression Inventory; SF-36: Short-Form 36; PHS: Physical Health Summary; MHS: Mental Health Summary.

Patients with comorbidities were reported to have impaired QoL (3). Our results were in line with this finding as children with urological problems had higher RSES scores in step 1, indicating lower self-esteem initially. As the parents also had higher BDI scores in only step 1, we speculate that the educational program might have positively modified the results by reversing incorrect beliefs regarding comorbidities in step 2.

Serum creatinine level is one of the contributing parameters to QoL (22,23). Our patients' creatinine levels were positively correlated to RSES scores only in step 1. Thus, these children may have felt guilty about their higher creatinine levels as they mostly had living donors. The educational program might have been beneficial as it fully

explained the post-RTx factors leading to impaired kidney function and this correlation was not present in step 2.

Low socioeconomic status exerts a negative impact on the HRQoL of RTx patients (22). The parents with lower monthly income had higher BDI scores only in step 1 ($P < 0.05$). It is thought that a better understanding of the fact that economic status was not related to the outcomes of the RTx might have eliminated the previous negative result in step 2.

In conclusion, although the sample size was small, our study revealed that pediatric RTx patients and their caregivers have favorable HRQoL. We think that continuous education and counseling are important in improving HRQoL in the posttransplant period.

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