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ORIGINAL ARTICLE

Quality of life in children with chronic kidney disease

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Abstract

Background Progressive chronic kidney disease (CKD), irrespective of the underlying etiology, affects the quality of life (QoL) of children due to the need for regular follow-up visits, a strict medication program and diet intake.

Methods The Greek version of the KIDSCREEN-52 multidimensional questionnaire was used in children with CKD, renal transplantation (RT) and in a control group (CG) of healthy children.

Results Fifty-five patients between 8 and 18 years, with CKD ($n = 25$), RT ($n = 16$) and with end-stage renal disease (ESRD) on peritoneal dialysis (PD) ($n = 14$) were included. Each group of studied children was compared with the CG ($n = 55$), the validation sample (VS) ($n = 1200$) and the parent proxy scores. Physical well-being of all studied children was significantly lower compared to CG ($p = 0.004$). In contrast, all studied children between 8 and 11 years showed better social acceptance compared to VS ($p = 0.0001$). When QoL of children with CKD was compared with parent proxy QoL, conflicting opinions were observed in several dimensions, such as self-perception ($p = 0.023$), autonomy ($p = 0.012$), school environment ($p = 0.012$) and financial resources ($p = 0.03$).

Conclusions QoL and mainly the dimension of physical well-being, may be affected dramatically in children with CKD unrelated to disease stage. In early school years children with CKD seem to feel higher social acceptance than the healthy controls, exhibiting better score in this dimension. Optimal care requires attention not only to medical management, but also to an assessment of QoL factors, that may help promote pediatric patient's health.

Keywords Quality of life · Questionnaire · Chronic kidney disease · Renal transplantation

Introduction

Chronic kidney disease (CKD) is rare in Greek children and according to the latest data from the European Society for Pediatric Nephrology, the incidence of end-stage renal disease (ESRD) is nine new cases per year per one million children and adolescents [1]. The diagnosis of such a serious disease as CKD has implications in many areas of life of both the children and their families, and can dramatically affect their quality of life (QoL). Many terms are used to describe QoL, however, based on a statement of the World Health Organization, QoL can be defined as "the individual's perception of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" [2]. The Kidney Disease Outcomes Quality Initiative (K/DOQI) reported in 2002 an association between impaired functioning and worse outcomes in CKD, suggesting regular assessment of functioning and well-being of all patients with a glomerular filtration rate of <60 ml/min/1.73 m^2 [3]. The estimation of health-related QoL (HRQoL) in children and adolescents has received

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increasing attention in pediatrics and adolescent health care, and several instruments/questionnaires are now available for use in these populations [4–7].

The optimal care and proper assessment of the health of children with CKD can be achieved if, apart from classic indicators such as mortality and morbidity, the personal perception of the state of their health is also taken into account. Therefore, the estimation of HRQoL in children with CKD and/or ESRD and pediatric renal transplant recipients would be particularly useful for a more accurate and complete evaluation and monitoring of these children. Unfortunately, the number of studies which have assessed HRQoL in such children is limited, mainly because it is very difficult to formulate the appropriate questions that properly reflect the assessment of HRQoL in children [4–7]. Moreover, to the best of our knowledge the HRQoL of children with CKD in Greece has not been assessed in comparable studies. Here we report our attempt to cover this gap in the literature in a study designed to record the HRQoL of children in Greece with CKD on peritoneal dialysis (PD) or who have had a renal transplant.

Methods

Design

This cross-sectional study of children and adolescents with CKD who were on PD or undergone renal transplantation (RT) was based on the completion of questionnaires as self-reports on participation and HRQoL and on proxy reports by the parents on their child's QoL. The study was conducted during a 4-month period from December 2013 to March 2014. It was esigned in accordance to the 1964 Helsinki declaration and its later amendments and was approved by the Special Committee on Survey Ethics of the Hippokratio General Hospital of Thessaloniki.

Patients

Study participants were children and adolescents aged from 8 to 18 years with CKD who were on PD or had undergone RT. CKD patients were classified in five stages according to the National Kidney Foundation [8]. Eligible for the study were CKD patients who had not sustained a change in their method of treatment over the last 3 months, or patients with ESRD on PD who had not sustained a change in their method of treatment during the last 2 months. Patients who had undergone RT and had a functioning graft for at least 1 year were also included. The control group consisted of healthy children aged 8–18 years with the same origin and proportion of males to females as the patient group; these children were asked to respond to the same questionnaire as the patient group. One of the authors, a medical doctor, was responsible for the questionnaire and was given information about the research project and procedures for collecting data and also informed patients and caregivers about the project. Parents of both the patients and healthy children gave their active informed consent regarding their child's participation.

Measures

Quality of life was measured using the Greek version of KIDSCREEN, a 52-item generic HRQoL measure. This questionnaire was designed for reporting by children and parents and can be used for healthy and chronically ill children and adolescents aged 8–18 years [9, 10]. The KIDSCREEN has already been used in a similar study of adolescent renal transplant patients in Belgium [11].

The KIDSCREEN-52 questionnaire in Greek uses a 5-point Likert scale where 1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = always, or as 1 = not at all, 2 = a little, 3 = moderate, 4 = much, 5 = too much, and; all ratings refer to observations and experiences of the last week. The questionnaire is also categorized into ten dimensions, including physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parental relations and home life, financial resources, peers and social support, school environment and bullying. For each domain, the relevant items are summed and scaled to yield a score ranging from 0 to 100, with higher scores indicating better QoL. The KIDSCREEN is a well-validated measurement tool that allows comparisons with the Greek general population [10]. Reference data are available for gender and two age groups, namely, 8–11 and 12–18 years [10].

During a scheduled outpatient clinic visit within the framework of re-evaluation because of their primary disease, participants were informed about the study and the questionnaire from a physician of the pediatric nephrology department. Once the parents and patients had been informed of the study and the protocol, written consent regarding participation was requested. Once written consent was obtained, The patient and parents were asked to complete the questionnaire in a separate room, during which time the physician was present and available for clarifications as necessary. The time required for completion of the questionnaire was 15–20 min.

Statistical analysis

Data recording, management and statistical analysis were conducted using SPSS (version 21.0) software (IBM Corp., Armonk, NY). The main analysis was performed according to the guidelines provided in the manual of the KIDSCREEN-52. Negatively worded questions were recoded and then transformed for each subject individually according to the Rasch model into Z-values and then into T-values. T-values were expressed in a mean scale 50 and a standard deviation (SD) of 10. Higher values correspond to higher HRQoL. The analysis was performed using Student's *t* test for independent samples, and an effect was considered to be statistically significant at $p < 0.05$.

Results

A total of 55 patients (27 boys, 28 girls) with a mean age of 13.14 ± 3.99 years participated in this cross-sectional study. Notable was that all patients and caregivers who were approached to participate in the study accepted the invitation. Patients were divided into three groups: (1) 16 patients who had undergone RT, (2) 14 patients with ESRD who were on PD and (3) 25 patients with CKD stage I–IV. The most common cause of CKD was renal dysplasia (11 patients), followed by focal glomerulonephritis (6 patients), multicystic kidneys and CKD of unknown etiology (5 patients each) and posterior urethral valves (4 patients); various causes were reported for the remaining patients. The demographic characteristics of the study participants are presented in Table 1.

Results from the assessment, analysis and comparison of the responses of children with kidney disease in the KIDSCREEN-52 questionnaire and data available from our weighted sample of the general Greek population for age groups 8–11 years and 12–18 years are presented in Table 2. It is noteworthy that children with renal disease in the age group 8–11 years had higher scores for the KIDSCREEN-52 dimension social acceptance that did children in the same age range in the weighted healthy population ($p = 0.0001$). In contrast, children with renal disease who were older (12–18) showed a tendency towards less social acceptance than those of the weighted healthy population ($p = 0.054$). Also for the dimension school environment, children with renal disease in the older age group showed a tendency for a more positive image than did those in the weighted healthy population ($p = 0.057$).

Assessment of the data from the responses of healthy controls, which are presented in Table 3, revealed that throughout the age range of 8–18 years the children with kidney disease in our study had lower physical well-being scores than the healthy controls ($p = 0.004$). The same trend was observed for the younger age group (8–11 years) of children with renal disease versus healthy controls ($p = 0.035$). On the contrary, there was no statistical difference in the physical well-being scores between the patients with renal disease and the healthy controls aged 12–18 years.

Results from the assessment and analysis of the responses of children with kidney disease compared to the responses of their parents are presented in Tables 4 and 5. In comparision to their parents, children who had undergone RT had significantly higher scores for the domain self-perception ($p = 0.04$) and better perception of the dimension financial resources ($p = 0.042$). Children with ESRD on PD scored higher in questions on their relationship with their parents in comparison to the parents themselves ($p = 0.031$). This same trend was observed in questions on the school environment, where the children's opinion was much more positive than the assessment of their parents ($p = 0.038$). It is noteworthy that children with kidney disease had significantly elevated scores compared to those of their parents in dimensions such as self-perception ($p = 0.023$), autonomy ($p = 0.012$), school environment ($p = 0.012$) and their financial resources ($p = 0.03$). Children with kidney disease in the age group 8–11 years had higher estimations for the dimension of self-perception than did their parents ($p = 0.044$), and those in the age group 12–18 years had a higher score than their parents in questions on the school environment ($p = 0.032$) and their financial resources ($p = 0.041$).

Children who had RT had significantly higher scores than children with CKD stages I–IV on the dimension financial resources ($p = 0.024$). Children with CKD on PD had a better appreciation for their own mood and emotions ($p = 0.002$), their relationship with their parents and their home life ($p = 0.001$) and their financial resources ($p = 0.001$) than did children with CKD stages I–IV.

Discussion

In this cross-sectional study, we have evaluated the QoL of children with CKD and ESRD and renal transplant recipients for the first time in Greece using multidimensional questionnaire that has been validated for the Greek population. Although the sample size is relatively small, it can be considered to be representative based on the demographics of the country. Measuring QoL of children with CKD is of particular importance since CKD is a chronic disease associated with specific treatments that dramatically affect the lifestyle of affected children.

Our findings show that in the 8- to 11-year age group children with kidney disease had higher social acceptance scores than did those in the validated sample of the Greek population [10]. On the contrary, in the at older age group (12–18 years), there was a tendency towards a lessgood social acceptance in children with kidney disease in comparison to the children in the validated sample. This result demonstrates that younger children with kidney disease do not feel intimidated, that they enjoy social acceptance by others and that they are treated with respect, probably due to a greater "sensitivity" for social relationships at these ages. Unfortunately, our study shows that these findings are reversed in older children, an observation also reported by Lopes et al. [12]. Moreover, adolescence comes with an increasing need for autonomy, privacy, socialization and social acceptance aspects that can be discommoded by the everyday conventional treatment program of a CKD

Table 1 Demographic characteristics of child self-reports and parent proxy-reports

Demographic characteristics	Patient population			
	RT (*n* = 16)	ESRD on PD (*n* = 14)	CKD stages I–IV (*n* = 25)	Total (*n* = 55)
Mean age (years)	14.38 (3.34)	12.13 (4.02)	12.61 (4.35)	13.14 (3.99)
Age 8–11 years, *n* (%)	4 (25)	10 (71.43)	12 (48)	26 (47.27)
Age 12–18 years, *n* (%)	12 (75)	4 (28.57)	13 (52)	29 (52.73)
Gender, *n* (%)				
Boys	6 (37.50)	8 (57.14)	13 (52)	27 (49.09)
Girls	10 (62.50)	6 (42.86)	12 (48)	28 (50.91)
Estimated GFR (ml/min/1.73 m^2)	87,21 (27.03)	11,71 (4.02)	63,85 (37.91)	57,35 (40.9)
Comorbidities, *n* %	5 (31.30)	6 (42.90)	3 (12)	14 (25.50)
Age at RT (years)	11.6 (2.8)	–	–	–
Mean follow-up time since RT (years)	3.3 (2.1)	–	–	–
Duration of dialysis therapy, during PD/before RT (months)	40.5 (22.6)	26.8 (14.9)	–	–
Age at onset of PD (years)	6.8 (2.7)	5.3 (3.1)	–	–
Family composition, *n* (%)				
Both parents, *n* (%)	14 (87.50)	14 (100)	25 (100)	53 (96.4)
Single parent, *n* (%)	2 (12.50)			2 (3.4)
Person who answered the questionnaire, *n* (%)				
Mother	14 (87.50)	11 (78.57)	20 (80)	45 (81.82)
Father	1 (6.25)	3 (21.43)	5 (20)	9 (16.36)
Sibling	1 (6.25)	–	–	1 (1.82)
Age (years)	40.5 (5.9)	38.7 (4.8)	39.4 (7.3)	39.5 (5.5)
Education (years)	11.9 (1.5)	13 (2.8)	12.4 (2.4)	12.3 (1.9)
Community, *n* (%)				
Urban	11 (68.75)	8 (57.15)	18 (72)	37 (67.27)
Rural	5 (31.25)	6 (42.85)	7 (28)	18 (32.73)
Economy status, *n* (%)				
Very satisfying	2 (12.50)	2 (14.30)	3 (12)	7 (12.73)
Good	8 (50)	7 (50)	16 (64)	31 (56.36)
Poor	4 (25)	5 (35.70)	6 (24)	15 (27.27)

Data are presented as the mean ± standard deviation (SD) unless indicated otherwise

CKD, Chronic kidney disease; ESRD, end stage renal disease; GFR, glomerular filtration rate; PD, peritoneal dialysis; RT renal transplantation

patient [12]. However, the findings of our study highlight that the QoL of children with kidney disease compared with the validated healthy Greek population is not severely impaired. This result is consistent and comparable to those of other studies conducted in different countries on pediatric patients with CKD versus the general population [13, 14].

When the QoL of children with CKD was compared with the data from the more limited sample of healthy controls, the former group of children had lower physical well-being scores, indicating that these children feel physically debilitated, have a poor physical condition and are less energetic. The interpretation of this finding could be related to the small number of healthy controls, since the finding was not replicated in the comparison with the validated sample. However, there are other notable published studies documenting that children with CKD report worse physical and psychosocial health compared to the general population despite the different studies using different questionnaires [12, 14]. Our finding of an absolute equality in the physical well-being assessment of children with CKD or ESRD on PD, renal transplant recipients and the validated sample remains striking and contrasts with nearly all other findings reported earlier. One possible explanation may be the interaction between the children and the adults who care for them, including parents, teachers and doctors in early life, all of whom play a determining role in the improvement of physical well-being. Moreover, it would appear that the parental role in the Greek family is of great importance in bestowing children with CKD or ESRD on PD and renal transplant recipients with a feeling of physical well-being equal to that of healthy children.

Discrepancies between the child-self and parent-proxy reports are documented in the present study. In general, children

Table 2 Comparison of quality of life scores of children with chronic kidney disease and the validated Greek population sample

KIDSCREEN-52 dimensions	Age group 8–18 years			Age group 8–11 years			Age group 12–18 years		
	Patients 8–18 years ($n = 55$)	Validated sample 8–18 years	p	Patients 8–11 years ($n = 26$)	Validated sample 8–11 years	p	Patients 12–18 years ($n = 29$)	Validated sample 12–18 years	p
Physical well-being	47.92 (10.29)	49.94 (9.88)	0.137	50.31 (10.13)	53.75 (9.99)	0.085	46.81 (10.35)	48.55 (9.66)	0.339
Psychological well-being	50.13 (10.73)	49.92 (9.87)	0.879	54.24 (10.78)	53.4 (9.39)	0.656	48.22 (10.33)	48.67 (9.93)	0.810
Moods and emotions	49.53 (10.92)	49.83 (9.7)	0.821	51.9 (9.9)	52.16 (10)	0.896	48.42 (11.36)	49.16 (9.9)	0.692
Self-perception	51.61 (9.39)	50.17 (10.18)	0.298	55.39 (6.66)	54.55 (9.78)	0.664	49.85 (10.04)	48.29 (9.57)	0.387
Autonomy	52.13 (9.37)	50.11 (10.14)	0.146	52.38 (9.99)	51.56 (9.72)	0.673	52.02 (9.24)	49.4 (10.06)	0.165
Parent relation and home life	50.2 (9.8)	50.13 (10.16)	0.962	50.01 (10.1)	52.66 (9.21)	0.151	50.29 (9.83)	48.96 (10.13)	0.485
Peers and social support	48.55 (10.35)	49.88 (9.95)	0.327	48.98 (10.78)	50.68 (10.11)	0.401	48.35 (10.33)	49.76 (10)	0.454
School environment	51.59 (9.19)	50.05 (10.14)	0.266	51.67 (9.44)	54.53 (10.49)	0.171	51.56 (9.23)	48.24 (9.26)	0.057
Social acceptance (bullying)	50.18 (10.47)	50.13 (10.16)	0.976	56.11 (8.52)	47.52 (10.6)	0.0001*	47.41 (10.25)	50.91 (9.64)	0.054
Financial resources	51.29 (7.44)	50.19 (10.21)	0.428	50.71 (8.95)	48.87 (10.49)	0.378	51.56 (6.78)	50.42 (9.81)	0.534

*Statistically significant difference at $p < 0.05$

Data are presented as the mean ± SD

at all ages evaluated themselves more positively than did their parents, suggesting a protected social and school environment. Differences between child-self and parent-proxy reports have been documented in most studies of QoL in CKD patients. In some studies the estimations of the children has been worse than those of their parents [15], but in most studies the parent-proxy scores were notably lower than those of their children [12, 16–19]. However, differences in study design (questionnaires utilized, age ranges, stage of disease) must always be taken into consideration. The assessment of QoL in both

Table 3 Comparison of quality of life scores of children with chronic kidney disease and the healthy control sample

KIDSCREEN-52 dimensions	Age group 8–18 years			Age group 8–11 years			Age group 12–18 years		
	Patients 8-18 years ($n = 55$)	Healthy controls 8–18 years ($n = 55$)	p	Patients 8–11 years ($n = 26$)	Healthy controls 8–11 years ($n = 24$)	p	Patients 12-18 years ($n = 29$)	Healthy controls 12–18 years ($n = 31$)	p
Physical well-being	47.92 (10.29)	54.55 (11.52)	0.004*	50.31 (10.13)	57.94 (10.5)	0.035*	46.81 (10.35)	51.93 (11.75)	0.076
Psychological well-being	50.13 (10.73)	49.04 (11.38)	0.628	54.24 (10.78)	52.74 (9.62)	0.662	48.22 (10.33)	46.17 (11.95)	0.478
Moods and emotions	49.53 (10.92)	49.51 (11.22)	0.993	51.9 (9.9)	53.69 (7.48)	0.533	48.42 (11.36)	46.27 (12.6)	0.488
Self-perception	51.61 (9.39)	51.89 (10.9)	0.891	55.39 (6.66)	53.91 (10.36)	0.637	49.85 (10.04)	50.33 (10.22)	0.86
Autonomy	52.13 (9.37)	50.76 (10.02)	0.488	52.38 (9.99)	52.44 (9.11)	0.985	52.02 (9.24)	49.46 (10.63)	0.321
Parent relation and home life	50.2 (9.8)	51.88 (8.59)	0.366	50.01 (10.1)	54.15 (7.31)	0.153	50.29 (9.83)	50.13 (9.19)	0.948
Peers and social support	48.55 (10.35)	50.26 (11.45)	0.442	48.98 (10.78)	52.79 (9.28)	0.258	48.35 (10.33)	48.31 (12.68)	0.99
School environment	51.59 (9.19)	53.16 (8.96)	0.395	51.67 (9.44)	56.06 (5.41)	0.128	51.56 (9.23)	50.91 (10.49)	0.799
Social acceptance (bullying)	50.18 (10.47)	50.22 (10.53)	0.984	56.11 (8.52)	51.69 (10.88)	0.201	47.41 (10.25)	49.09 (10.23)	0.527
Financial resources	51.29 (7.44)	53.49 (5.78)	0.111	50.71 (8.95)	53.18 (6.12)	0.37	51.56 (6.78)	53.74 (5.59)	0.177

*Statistically significant difference at $p < 0.05$

Table 4 Comparison of child self-reports and parent proxy-reports in children with kidney disease

KIDSCREEN-52 dimensions	RT children			Children with ESRD on PD			Children with CKD stages I–IV			All renal patients		
	Child self-report (*n* = 16)	Parent-proxy report	*p*	Child self-report (*n* = 14)	Parent-proxy report	*p*	Child self-report (*n* = 25)	Parent-proxy report	*p*	Child self-report (*n* = 55)	Parent-proxy report	*p*
Physical well-being	47.9 (13.23)	51.54 (12.5)	0.431	47.46 (7.39)	49.59 (5.6)	0.467	48.1 (8.94)	47.9 (5.76)	0.932	47.92 (10.29)	49.39 (8.26)	0.434
Psychological well-being	48.66 (12.02)	49.32 (9.47)	0.866	54.61 (10.64)	51.81 (7.5)	0.491	49.76 (9.82)	50.13 (8.46)	0.891	50.13 (10.73)	50.32 (8.44)	0.924
Moods and emotions	49.71 (12.24)	48.79 (9.45)	0.814	55.95 (2.34)	52.65 (7.48)	0.149	47.25 (11.08)	51.07 (7.82)	0.179	49.53 (10.92)	50.81 (8.22)	0.508
Self-perception	51.1 (10.08)	43.29 (10.52)	0.04*	53.77 (8.39)	48.78 (9.23)	0.244	51.28 (9.5)	48.65 (9.32)	0.35	51.61 (9.39)	47.12 (9.8)	0.023*
Autonomy	52.49 (11.32)	47.77 (11.66)	0.255	51.48 (8.31)	43.04 (11.36)	0.098	52.08 (8.48)	48.85 (8.16)	0.196	52.13 (9.37)	47.06 (10.21)	0.012*
Parent relation and home life	51.79 (8.66)	47.86 (13.93)	0.346	56.48 (2.85)	49.65 (10.03)	0.031*	46.9 (10.98)	48.96 (9.55)	0.499	50.2 (9.8)	48.82 (10.92)	0.514
Peers and social support	49.93 (12.46)	53.44 (6.54)	0.329	48.54 (7.6)	52.55 (10.11)	0.368	47.5 (9.7)	49.91 (8.93)	0.395	48.55 (10.35)	51.67 (8.61)	0.108
School environment	52.12 (9.73)	49.7 (10.86)	0.51	49.65 (7.26)	41.2 (8.56)	0.038*	51.84 (9.65)	47.23 (10.79)	0.144	51.59 (9.19)	46.38 (10.61)	0.012*
Social acceptance (bullying)	51.74 (11.26)	52.31 (9.43)	0.877	45.43 (8.99)	51.67 (5.37)	0.059	50.58 (10.3)	45.65 (12.59)	0.162	50.18 (10.47)	50.15 (7.89)	0.987
Financial resources	53.61 (6.17)	47.12 (10.38)	0.042*	55.65 (2.62)	50.21 (9.58)	0.161	48.07 (8.16)	44 (16.39)	0.31	51.29 (7.44)	46.58 (13.2)	0.03*

RT renal transplant, *ESRD* end stage renal disease, *PD* peritoneal dialysis, *CKD* chronic kidney disease

*Statistically significant difference at $p < 0.05$

Data are presented as the mean ± SD

patients and caregivers is important for the complete psychosocial support of both. In addition, the continuous involvement of parents, who are trained and implement the PD program on a daily basis, often leads to burnout. Therefore, the assessment of QoL is very important in the decision-making process regarding medical treatments, affecting not only children but also their families. This is one of the reasons for several significant differences in QoL scores reported by parents in comparison to the child's self-report, since different QoL patient scores could be evaluated as signs of non-adherence. Therefore, physicians should periodically pay attention to the results of QoL assessments of patients with CKD.

The undoubted discordance between child-self and parent-proxy estimations could indicate specific areas of miscommunication between family members. Most of the disparities in the assessment of QoL among children and their parents occur during adolescence, possibly attributable to the fact that adolescents exhibit an increased tendency to independence as well as to the difficulty adolescent patients with chronic diseases experience in expressing feelings and thoughts to their family. This pattern of behavior could easily lead the adolescent CKD patient down the path towards isolation, psychological imbalance and ultimately in failure of compliance to any kind of treatment. Another aspect that should be highlighted is that caregivers either tend to underestimate the effects of the disease on their children's QoL or they feel rather constricted by the ongoing obligations in favor of their offspring's well-being, shifting the results respectively.

Our evaluation and analysis of the several scores among different groups of children with kidney disease revealed that there is no significant difference in QoL between children with CKD on PD and pediatric renal transplant recipients versus healthy controls or the validated sample. This finding may be associated with the full awareness of the nature of the disease and the relative ease of PD (night program) that results in better coping mechanisms. Similar QoL scores between children on dialysis/pediatric renal transplant recipients and the general population have also been reported by Eijsermans et al. [13]. A similar finding has also been reported from a study performed in China in which, as in our study, a concordance was observed between the total score of QoL in children on PD and children who received a renal transplant [14]. The authors of this study also reported the same association as found in our study for the parent-proxy scores [14]. However, other published studies have reported different results. In 2006 Goldstein et al. reported that QoL scores were significantly lower in ESRD patients than in healthy controls [20]; these results were subsequently confirmed by the same study group in 2009 [21] and by Buyan et al. in 2010 [15].

On the other hand, we found that the reported QoL scores of the pediatric renal transplant recipients in the dimension of financial resources were higher than those of children with CKD stage I–IV. However, this sense of satisfaction deriving

Table 5 Comparison of child self-reports and parent proxy-reports

KIDSCREEN-52 dimensions	Age group 8–11 years			Age group 12–18 years		
	Patients 8–11 years ($n = 26$)	Parent-proxy of patients 8–11 years	p	Patients 12–18 years ($n = 29$)	Parent-proxy of patients 12–18 years	p
Physical well-being	47.4 (11.28)	50.23 (11.54)	0.428	48.56 (9.49)	48.14 (7.61)	0.849
Psychological well-being	49.66 (11.32)	49.32 (9.37)	0.899	51.58 (9.67)	50.97 (8.47)	0.631
Moods and emotions	47.68 (11.14)	48.88 (9.45)	0.494	53.75 (6.54)	51.69 (8.52)	0.549
Self-perception	49.1 (11.18)	43.69 (8.77)	0.044*	53.58 (8.44)	48.99 (11.93)	0.174
Autonomy	52.14 (10.92)	47.93 (11.89)	0.059	51.96 (8.31)	44.68 (9.63)	0.068
Parent relation and home life	51.69 (9.54)	47.73 (11.45)	0.246	49.48 (7.95)	49.93 (10.13)	0.874
Peers and social support	49.73 (11.4)	51.49 (8.65)	0.334	48.45 (8.16)	52.78 (9.11)	0.284
School environment	51.22 (10.31)	49.18 (9.68)	0.319	51.55 (9.66)	42.32 (10.96)	0.032*
Social acceptance (bullying)	49.53 (11.62)	50.79 (9.39)	0.819	50.13 (8.46)	51.18 (5.89)	0.889
Financial resources	49.66 (8.71)	47.24 (9.58)	0.352	52.99 (8.62)	45.21 (6.59)	0.041*

*Statistically significant difference at $p < 0.05$

Data are presented as the mean ± SD

from their financial resources and the enhanced feeling of well-being observed in children who had received a renal transplant is most likely fictitious and this feeling of satisfaction is probably a result of their psychological well-being that also encompasses such feelings as pleasure irrespective of the actual financial potential.

We also observed that children with CKD on PD scored higher in the dimensions mood and feelings, relationship with their parents and home life and financial resources than children with CKD stages I–IV. Additionally, most published studies acknowledge that the biggest difference in QoL scores is observed between alternative methods of renal replacement therapy, i.e., hemodialysis versus PD, with the first being characterized by a lower level of QoL for children [15, 20, 22, 23].

Advances in technology and medical care have remarkably improved the long-term survival rates of children with CKD [14]. Inevitably this fact has led current research towards investigating a more longstanding aspect of QoL in CKD patients. Neul et al. reported that broad-based estimations of global and disease-related QoL functioning remained fairly stable across their 2-year assessment period and that patients tended to have overall more positive appraisals of their functioning compared to their parents [19]. Mekahli et al. studied young adults who have lived with severe CKD from infancy and reported that these patients can expect a HRQoL comparable to that of a normal population with good prospects of education and employment [24]. Data from these types of surveys could be used to inform families about the future of their children and to detect trends about which therapeutic strategies provide the best possible QoL for CKD children and their families.

In conclusion, QoL and mainly the dimension of physical well-being may be affected dramatically in children with CKD, unrelated to disease stage. Other dimensions of HRQoL are slightly or even not affected at all. On the contrary, in young school-age children with CKD seem to be protected by their social environment of schoolmates, which is reflected in their feeling of higher social acceptance than that of the healthy controls. In this context, with the aim of improving QoL, it is necessary to regularly evaluate the QoL status of these children, to identify new risk factors that could possibly affect this status and to assess any ameliorative intervention for any of the dimensions that determine QoL.

Compliance with ethical standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors declare that they have no conflict of interest.

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