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ORIGINAL ARTICLE

Illness-related parental stress and quality of life in children with kidney diseases

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Abstract

Background This cross-sectional study investigated quality of life (QoL) and illness-related parental stress in children with kidney diseases by (1) comparing mean levels of these two variables between several kidney disease categories; (2) exploring correlations between QoL and parental stress; and (3) describing which disease category reports lowest QoL and highest parental stress.

Methods We included 295 patients with a kidney disease (0–18 years) and their parents, followed at 6 reference centers for pediatric nephrology. Children's QoL was assessed by the PedsQL™ 4.0 Generic Core Scales, and illness-related stress by the Pediatric Inventory for Parents. All patients were divided into 5 kidney disease categories according to the multidisciplinary care program criteria prescribed by the Belgian authorities: (1) structural kidney diseases, (2) tubulopathies and metabolic diseases, (3) nephrotic syndrome, (4) acquired diseases with proteinuria and hypertension, and (5) kidney transplantation.

Results Child self-reports showed no differences in QoL between kidney disease categories, in contrast to parent proxy reports. Parents of transplant patients reported lower QoL in their child and more parental stress compared with the 4 non-transplant categories. QoL and parental stress were negatively correlated. Lowest QoL and highest parental stress scores were mainly found in transplant patients.

Conclusions This study showed lower QoL and higher parental stress in pediatric transplant patients compared with non-transplants, based on parent reports. Higher parental stress is associated with worse QoL in the child. These results highlight the importance of multidisciplinary care for children with kidney diseases, with special attention to transplant patients and their parents.

Keywords Children · Kidney disease · Quality of life · Illness-related parental stress · Transplantation · Multicentric

Elke De Bruyne and Lore Willem contributed equally to this work (shared first authorship); and Evelien Snauwaert and Elena Levtchenko contributed equally to this work (shared last authorship).

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Abbreviations

CKD	Chronic kidney disease
QoL	Quality of life
eGFR	Estimated glomerular filtration rate

Introduction

Kidney diseases in childhood can have a major impact on patients and their parents. Despite medical, surgical, and nutritional advances resulting in higher survival rates [1, 2], the psychosocial development of these patients and families is affected, especially when accompanied by a significant loss of glomerular filtration [3, 4]. Also, studies including patients with mild chronic kidney disease (CKD) stages, nephrotic syndrome or after kidney transplantation reported more psychological problems compared with healthy controls, showing that not only children with kidney failure are impacted [4–7]. Next to medical treatment, monitoring quality of life (QoL) is perceived as one of the most important goals in patient care. The majority of studies report worse QoL in children with kidney diseases compared with healthy children, and parent proxy reports often result in even lower QoL than child self-reports [2–5, 8, 9]. In addition, higher levels of burden and more symptoms of anxiety and depression are described in parents of CKD patients [10–13]. Moreover, parental stress has been associated with lower QoL scores in the child, but also other poorer psychological outcomes such as lower adherence to immunosuppressant medications and a higher presence of behavioral problems [14, 15].

Only a few studies have explored differences in QoL or parental stress between different kidney diseases or CKD stages. According to Abrao et al., parents of transplant patients reported lower QoL and higher occurrence of psychiatric diagnoses in their child than parents of children with CKD stage 3–4 and children on dialysis [15]. Another study found children after kidney transplantation to report an equally impaired level of QoL as children on dialysis [16]. Similar studies concluded that, although kidney transplantation was related to many improvements in health condition, parents still reported significant psychological distress [17, 18].

More than a decade ago, Belgian authorities identified this psychosocial need by creating a multidisciplinary care program not only for patients with advanced CKD (stages IV–V not on dialysis) but also for children with tubulopathies and metabolic diseases, severe nephrotic syndromes, acquired diseases with proteinuria and hypertension, and transplant patients. (Please see Appendix for the detailed criteria and definitions of this kidney disease classification of the Belgian multidisciplinary care program.) Besides medical and nutritional follow-up, this care program provides reimbursed paramedical support (by psychologists, specialized nurses, and social workers) for all these patients and their families being followed in one of the 6 Belgian reference centers for pediatric nephrology.

The primary objective of this cross-sectional multicentric study was to investigate QoL and illness-related parental stress in children with kidney diseases by (1) comparing the mean levels of these two variables between several kidney disease categories, according to the official multidisciplinary care program criteria; (2) exploring associations between QoL and parental stress; and (3) identifying which disease category reports lowest QoL and highest parental stress.

Our secondary objective was to explore several additional parameters (child's age, duration of kidney disease, time since kidney transplantation, preemptive or non-preemptive transplantation, duration of dialysis before transplantation) in relation to child's QoL and parental stress.

Methods

Study population

This cross-sectional study was conducted in 2019 and included children with kidney diseases and their parents, followed at the Belgian reference centers for pediatric nephrology, i.e.: Leuven University Hospital, Ghent University Hospital, Antwerp University Hospital, Queen Fabiola Children's University Hospital Brussels, Saint-Luc Brussels University Hospital, and CHC-MontLégia Health Group Liège. All 6 centers provide multidisciplinary care for children with kidney diseases, reimbursed by the Belgian authorities. Each multidisciplinary team consists of pediatric nephrologists, specialized nurses, psychologists, social workers, and dieticians, who provide follow-up consultations for these patients and their families on a structural basis, ranging from 4 outpatient clinics per year to weekly clinics, depending on the specific need.

Inclusion criteria for this study were defined as children (5–18 years old) with a kidney disease, and parents of children (0–18 years old, with a kidney disease). All parents surveyed were the primary caregivers of the patient and were therefore able to provide adequate information about their child. Each patient was, according to his or her primary diagnosis, attributed to one of the 5 kidney disease categories according to the official multidisciplinary care program criteria: (1) children with structural kidney diseases (congenital or hereditary, younger than 1 year old or with CKD stages IV–V but not on dialysis); (2) tubulopathies and metabolic diseases; (3) nephrotic syndromes (congenital, steroid resistant or steroid sensitive with more than 3 relapses); (4) acquired diseases with proteinuria and hypertension; and (5) kidney transplantation (Table 1). Patients with a kidney transplant were automatically included in the transplant category, regardless of their underlying diagnosis or time

Table 1 Clinical and demographic data of patients

	Child self-reports ($N=295$)	Parent proxy reports ($N=285$)
	Mean ± SD	Mean ± SD
Child's age (year)	11.8 ± 3.7	10.5 ± 4.5
Age range	5–18	0–18
Duration of kidney disease	8.1 ± 4.9	7.3 ± 4.9
Months on dialysis before transplant	15.0 ± 11.5	16.2 ± 13.5
	N (%)	*N* (%)
Child's gender (%)		
- Male	176 (60)	170 (60)
- Female	119 (40)	114 (40)
- Missing	0 (0)	1 (0)
Child's place of birth		
- Belgium	277 (94)	264 (93)
- Outside Belgium	18 (6)	20 (7)
- Missing	0 (0)	1 (0)
Parent's marital status		
- Married/living together	181 (61)	167 (58.5)
- Divorced	61 (21)	51 (18)
- Widow(er)	5 (2)	3 (1)
- Unmarried/living apart	8 (3)	7 (2.5)
- Newly formed family	8 (3)	10 (3.5)
- Missing	32 (11)	47 (16.5)
Kidney disease category*		
- Structural kidney diseases	42 (14)	58 (20)
- Tubulopathies and metabolic diseases	53 (18)	48 (17)
- Nephrotic syndrome	69 (23)	60 (21)
- Acquired diseases with proteinuria and hypertension	74 (25)	65 (23)
- Kidney Transplantation	57 (19)	53 (19)
- Missing	0 (0)	1 (0)
Stage CKD		
- Stage 1 (> 90 mL/min/1.73 m^2)	147 (50)	132 (46)
- Stage 2 (60–89 mL/min/1.73 m^2)	74 (25)	75 (26)
- Stage 3 (30–59 mL/min/1.73 m^2)	56 (19)	56 (20)
- Stage 4 (15–29 mL/min/1.73 m^2)	6 (2)	9 (3)
- Stage 5 (< 15 mL/min/1.73 m^2)	1 (0)	2 (1)
- Missing	11 (4)	11 (4)
Years since transplant ($N=57$; $N=53$)		
- Within year	10 (18)	12 (23)
- Longer than 1 year	47 (82)	41 (77)
Preemptive transplant ($N=57$; $N=53$)		
- Yes	14 (25)	13 (24.5)
- No	41 (72)	39 (73.5)
- Missing	2 (3)	1 (2)
Duration dialysis before transplant ($N=41$; $N=39$)		
- < 1 year	21 (51)	19 (49)
- > 1 year	20 (49)	20 (51)
- Missing	0 (0)	0 (0)

*According to the official multidisciplinary care program criteria, prescribed by the Belgian authorities for all reference centers for pediatric nephrology

N, number; *SD*, standard deviation; *CKD*, chronic kidney disease

since transplantation. Exclusion criteria for this study were defined as severe cognitive and developmental disability or an insufficient knowledge of Dutch or French.

The questionnaires used for this study were administered to the patients and one of his/her parents once a year as part of standard clinical care, as all reference centers support the

value of using psychosocial measurement tools to explore the well-being of these families on a structural basis. Patients and parents could refuse participation at all times without consequences for their treatment. Additional medical information of the patients was retrieved from their medical files. For each patient, the estimated glomerular filtration rate (eGFR) was calculated using the bedside Schwartz formula (eGFR = 0.413 × length/creatinine (Mg/dL)) so the patients could be subdivided in CKD stages 1 to 5 (Table 1) [19].

The multicentric study was approved by the Ethics Committees of all reference centers, with Leuven University Hospital as the central Ethics Committee (Ethics approval number: S61593).

Measures

PedsQL™ 4.0 Generic Core Scales

Childrens' QoL was assessed by the PedsQL™ 4.0 Generic Core Scales [20], a well-known and valid instrument to assess general QoL in healthy or chronically ill children [20, 21]. This questionnaire has been recently validated for a Dutch-speaking Belgian population of children with kidney diseases [5]. For the French-speaking patients and their parents, a validated French version was administered [22]. This questionnaire consists of 4 functional domains: Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning. These last 3 domains form the Psychosocial subscale. The Total subscale consists of the Physical and Psychosocial subscale. Each item was rated on a five-point Likert scale ranging from 0 ("never a problem") to 4 ("always a problem"). For each item, scores were converted and linearly transformed to a 0–100 scale (0 = 100 for "never," 1 = 75 for "almost never," 2 = 50 for "sometimes," 3 = 25 for "a lot," 4 = 0 for "almost always'), with higher scores representing a better QoL. The PedsQL™ 4.0 Generic Core Scales contain two formats: a child self-report for participants between 5 and 18 years of age (5–7 years; 8–12 years; 13–18 years) and a parent proxy report for parents of participants between 2 and 18 years of age (2–4 years; 5–7 years; 8–12 years; 13–18 years) [20, 21]. Studies have shown good internal consistency for all scales [23], and also specifically for a Belgian population of children with kidney diseases [5]. Parents of children from the age of 2, and children from the age of 5 were asked to complete the PedsQL™ 4.0 Generic Core Scales.

Pediatric Inventory for Parents (PIP)

Illness-related parental stress was measured by the Pediatric Inventory for Parents (PIP) [24, 25]. Parents were asked to report the frequency and perceived difficulty of 42 stressful events that are related to parenting a child with a chronic illness, on a 5–point Likert scale ranging from "never" to "very often" for frequency, and "not at all" to "extremely" for difficulty. The PIP consists of 5 subscales: (1) communication with the child/medical team (i.e., speaking with the child about his/her illness, talking with a doctor or nurse); (2) emotional distress (i.e., feeling uncertain about the future, learning upsetting news); (3) medical care (i.e., helping my child with medical procedures, making decisions about medical care or medicines); and (4) role functioning (i.e., trying to attend to the needs of other family members, feeling uncertain about disciplining my child). The Total scale has a possible score range from 42–210, with higher scores indicating more illness-related parental stress. The Dutch and French version of the PIP has shown satisfactory psychometric qualities [25, 26], and it has been used in several other pediatric conditions, such as cancer [24], type 1 diabetes [27], inflammatory bowel diseases [28], and heart transplantation [29]. The PIP was filled in only by the parents, regardless of the child's age.

Statistical methods

All statistical analyses were examined by using SPSS 28.0. Patient characteristics were explored using descriptive analyses.

Normality was checked with the Shapiro–Wilk test. Continuous data are reported as median and interquartile range (IQR) scores, or as mean scores and standard deviations (SD) when appropriate. Kidney disease categories were compared using the Anova or Kruskal–Wallis test. Differences between the total group of non-transplant patients (i.e., structural kidney diseases, tubulopathies and metabolic diseases, nephrotic syndrome, and acquired diseases with proteinuria and hypertension) and transplant patients were compared with the *t* test or Mann–Whitney *U* test, depending on data distribution.

Correlations between QoL and parental stress, and between child self-reports and parent proxy reports were measured by using Pearson's correlation coefficients. Effect sizes are designated as small (0.10–0.29), medium (0.30–0.49), or large (≥ 0.50) [30].

To identify which kidney disease categories report highest or lowest levels of QoL and parental stress, two new groups (highest QoL and lowest stress; lowest QoL and highest stress) were created based on the median scores of the total scores of parent proxy reports of the PedsQL™ 4.0 Generic Core Scales and the total frequency scores of the PIP. Scores below the median on these questionnaires were categorized as low, scores equal, or above the median were categorized as high.

Finally, to assess differences between age groups, the participants were divided into 3 age groups (0–4 years; 5–12 years; 13–18 years). Child self-reports of the PedsQL,

parent proxy reports of the PedsQL, and parent reports of the PIP were compared between these 3 age groups by means of Anova or Kruskal–Wallis test, depending on the distribution of the data.

Results

Clinical and demographic data

The characteristics of the 295 included patients (age 11.8 ± 3.7 years) and the 285 parents are provided in Table 1.

The majority of children were male (60%), born in Belgium (94%), and had parents still married or living together (61%). Patients were approximately equally distributed over the 5 kidney disease categories (ranging from 14 to 25%). Children had been diagnosed with their kidney disease for an average of 8.1 (± 4.9) years. In case of kidney transplantation, most transplantations were performed longer than 1 year before the study (82%). The majority of the transplantations were non-preemptive (72%), with a mean duration of 15 (± 11.5) months on dialysis before transplantation.

Figure 1 visualizes the distribution of CKD stages across different kidney disease categories. Most children with tubulopathies and metabolic diseases, nephrotic syndrome, and acquired diseases with proteinuria and hypertension had CKD stage 1 or 2. In the transplant group, most patients had CKD stage 2 or 3. Moreover, transplant patients had a higher proportion of patients with CKD stage 3 than the other categories. Almost all patients with CKD stages 4 and 5 belonged to the category structural kidney diseases.

Differences in child's quality of life

Regarding the primary objectives, the median and IQR scores of child's QoL, based on child self-reports and parent proxy reports of the PedsQL™ 4.0 Generic Core Scales, are summarized in Table 2 for all 5 kidney disease categories, and in Table 3 for non-transplant patients and transplant patients.

For the child self-reports, no significant differences in QoL could be detected between the 5 kidney disease categories, neither for the total scale nor for the 2 subscales, i.e., the psychosocial and physical scales (Table 2). Similarly, we found no significant QoL differences between non-transplant and transplant patients (Table 3).

In contrast, parent proxy reports demonstrated significant differences between the kidney disease categories on total QoL and physical QoL (Table 2). Also, results showed significantly lower total, physical and psychosocial QoL in transplant patients compared with the non-transplant patients (Table 3).

Regarding the secondary objectives, duration of kidney disease was not significantly correlated with child's QoL, neither for the child self-reports nor for the parent proxy reports. No significant differences in QoL between age groups were detected, neither for the child self-reports (5–12 years; 13–18 years), nor for the parent proxy reports (0–4 years; 5–12 years; 13–18 years).

Further exploration in the transplant group showed no significant differences in total QoL (based on both child self-reports and parent proxy reports) between children with a preemptive transplant and children with a non-preemptive

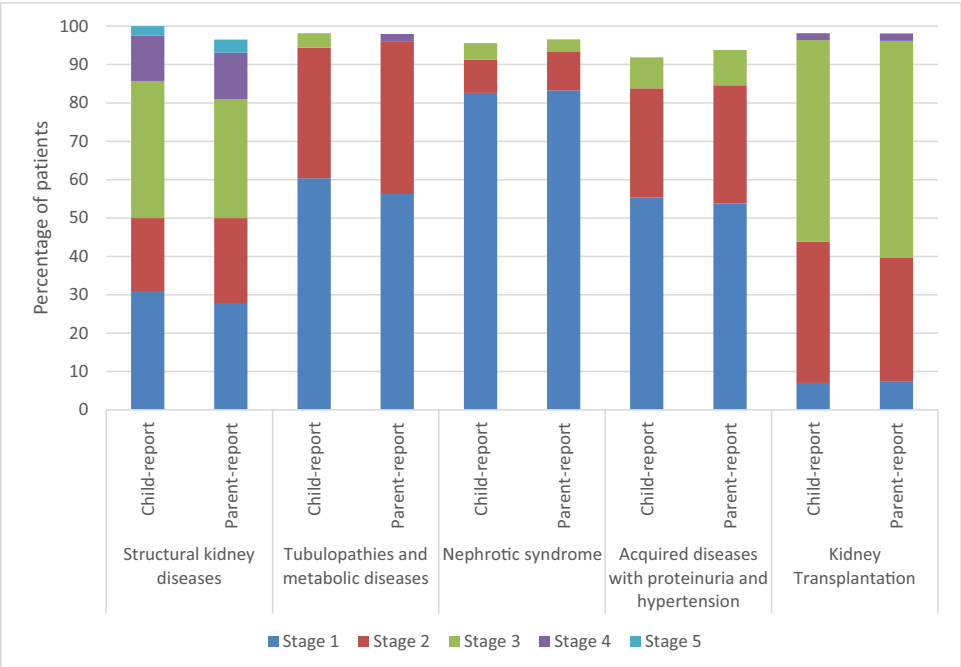

Fig. 1 Distribution of chronic kidney disease stages across kidney disease categories

Table 2 Median scores of PedsQL^{TM} 4.0 Generic Core Scales and mean scores of Pediatric Inventory for Parents

	Total group		Structural kidney diseases		Tubulopathies & metabolic diseases		Nephrotic syndrome		Acquired diseases with hypertension and proteinuria		Kidney Transplantation		Test (df)	*P*
Scale	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)		
PedsQL^{TM} 4.0 Core														
Child Self-Reports													H (4)	
Physical	295	75 (56.3-87.5)	42	75 (55.5-87.5)	53	81.3 (43.8-93.8)	69	78.1 (62.5-87.5)	74	75 (58.6-87.5)	57	75 (56.3-81.3)	0.76	.94
Psychosocial	295	70 (53.3-80)	42	71.7 (61.3-82.1)	53	68.3 (44.2-80)	69	70 (58.3-78.3)	74	70 (52.9-82.1)	57	70 (53.3-80)	0.85	.93
Total	295	72.5 (57.5-82.8)	42	69 (60.5-84.4)	53	70 (51-84.4)	69	73.2 (61.3-81.6)	74	71.6 (59-83.8)	57	73.3 (56.6-80.2)	0.42	.98
Parent Proxy-Reports													H (4)	
Physical	225	75 (56.3-90.6)	45	75 (56.4-92.2)	36	76.6 (53.9-87.5)	48	75 (60.2-89.8)	50	81.3 (64.1-93.8)	46	62.5 (43.8-78.9)	10.27	.04
Psychosocial	225	65.4 (55-76.7)	45	66.7 (57.2-77.5)	36	64.2 (58.3-76.3)	48	68.3 (55.4-78.3)	50	70 (54.2-82.1)	46	60.8 (45-73.8)	7.63	.11
Total	225	69.2 (55.4-82.2)	45	68.9 (58-83.1)	36	72.3 (52.5-82.4)	48	69.3 (55.5-84.2)	50	75.9 (61.3-84.1)	46	58.5 (46.1-75)	12.18	.02
Pediatric Inventory for Parents													F(4,269)	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)		
Total Frequency	275	100.1± 30.9	56	104.0 ± 26.6	45	94.1 ± 25.3	57	102.1 ± 37.4	63	92.0 ± 30.8	53	108.8 ± 30.1	2.92	.02

Higher median or mean scores indicate better quality of life or higher illness-related parental stress, respectively.

df, degrees of freedom; P, p-value; N, number; IQR, interquartile range; H, Kruskal–Wallis H test; F, F-value; SD, standard deviation

Table 3 Median scores of PedsQL™ 4.0 Generic Core Scales and mean scores of Pediatric Inventory for Parents of non-transplant patients and transplant patients

	Non-transplant patients*		Transplant patients		Test (df)	
Scale	N	Median (IQR)	N	Median (IQR)	*U*	*P*
PedsQL™ 4.0 Core						
Child Self-Reports						
Physical	238	78.1 (56.3-87.5)	57	75 (56.3-81.3)	6382.5	.49
Psychosocial	238	70 (54.6-80)	57	70 (53.3-80)	6777.5	.99
Total	238	72.5 (58.4-83.7)	57	73.3 (56.6-80.2)	6521.5	.65
Parent Proxy-Reports						
Physical	179	75 (59.4-90.6)	46	62.5 (43.8-78.9)	2973.5	.004
Psychosocial	179	66.7 (56.7-80)	46	60.8 (45-73.8)	3101.5	.01
Total	179	71.5 (57.7-83)	46	58.5 (46.1-75)	2851.5	.001
Pediatric Inventory for Parents						
	N	Mean (SD)	N	Mean (SD)	t (273)	
Total Frequency	222	98 (30.8)	53	108.8 (30.1)	-2.3	.02

Higher mean or median scores indicate better quality of life and higher illness-related parental stress, respectively.

* Kidney disease categories 1–4 according to the official multidisciplinary care program criteria, prescribed by the Belgian authorities for all reference centers for pediatric nephrology; i.e. structural kidney diseases, tubulopathies and metabolic diseases, nephrotic syndrome, acquired diseases with proteinuria and hypertension.

df, degrees of freedom; N, number; IQR, interquartile range; U, Mann–Whitney test; P, p-value; SD, standard deviation; t, t-test

transplant, between children with a preemptive transplant and children with a transplant after less than 1 year on dialysis, or between children who had a recent kidney transplant (i.e., within 1 year) and children with a kidney transplant longer than 1 year ago. Duration of dialysis before transplantation was not significantly correlated with child's total QoL when reported by the child, but significantly negatively correlated with child's total QoL when reported by the parents ($r = -0.4$; $p < 0.05$).

Differences in illness-related parental stress

Regarding the primary objectives, the mean scores of illness-related parental stress for all kidney disease categories based on the PIP are shown in Table 2, and in Table 3 for non-transplant and transplant patients.

Similar to QoL, parent reports showed significant differences in parental stress between the different kidney disease categories (Table 2). In addition, parents of transplant patients reported significantly higher levels of stress compared with parents of patients who never received a kidney transplant (Table 3).

Regarding the secondary objectives, duration of kidney disease was significantly negatively correlated to parental stress ($r = -0.2$; $p < 0.05$). No significant differences in parental stress between the 3 age groups (0–4 years; 5–12 years; 13–18 years) were detected.

Further exploration in the transplant group showed no significant differences in parental stress between parents of children transplanted preemptively or after a period of dialysis. Neither time since transplantation nor duration of dialysis before transplantation significantly impacted the parental stress.

Correlations

As displayed in Figs. 2 and 3, correlation analyses indicated significant negative correlations between parental stress (based on the total frequency score of the PIP) and child's total QoL, based on both parent proxy reports (Fig. 2) and child self-reports (Fig. 3) of the PedsQL™ 4.0 Generic Core Scales. However, a stronger correlation was found in the parent reports ($r = -0.6$) compared to the child reports ($r = -0.2$).

Additionally, a significant positive correlation between the child self-reports and parent proxy reports of the total QoL scale of the PedsQL™ 4.0 Generic Core Scales could be detected ($r = 0.6$) (Fig. 4).

Highest and lowest levels of child's QoL and parental stress

Figure 5 visualizes the distribution of lowest and highest levels of child's QoL and parental stress over all 5 kidney disease categories. The combination of lowest levels of QoL and highest levels of parental stress was most present in transplant patients ($n = 23$), whereas the combination of highest QoL levels and lowest parental stress levels was most

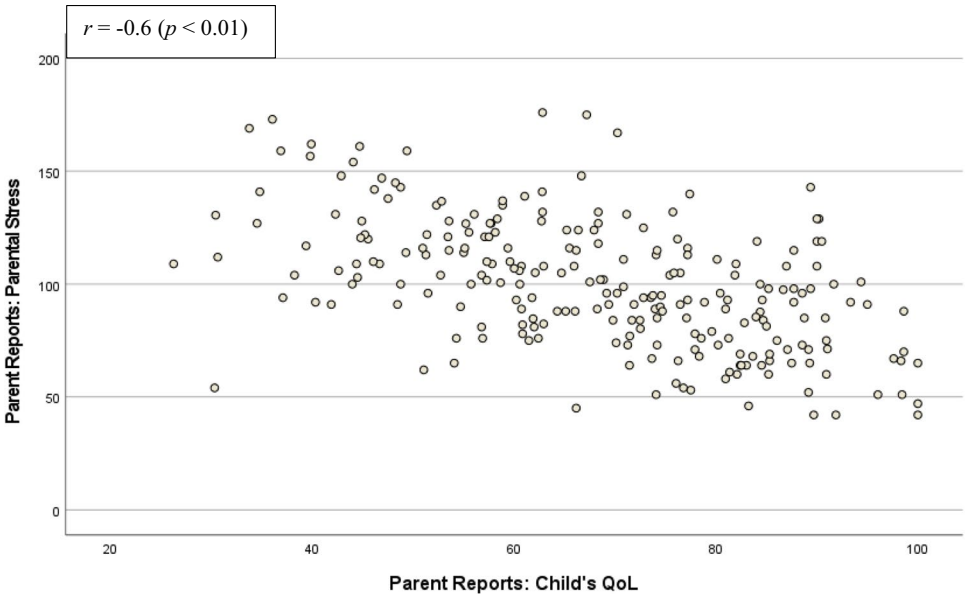

Fig. 2 Pearson's correlations between total scores of parent proxy-reports of PedsQL.™ 4.0 Generic Core Scales and total frequency scores of Pediatric Inventory for Parents ($N = 219$)

N, number; *r*, Pearson's correlation coefficient; *p*, p-value.

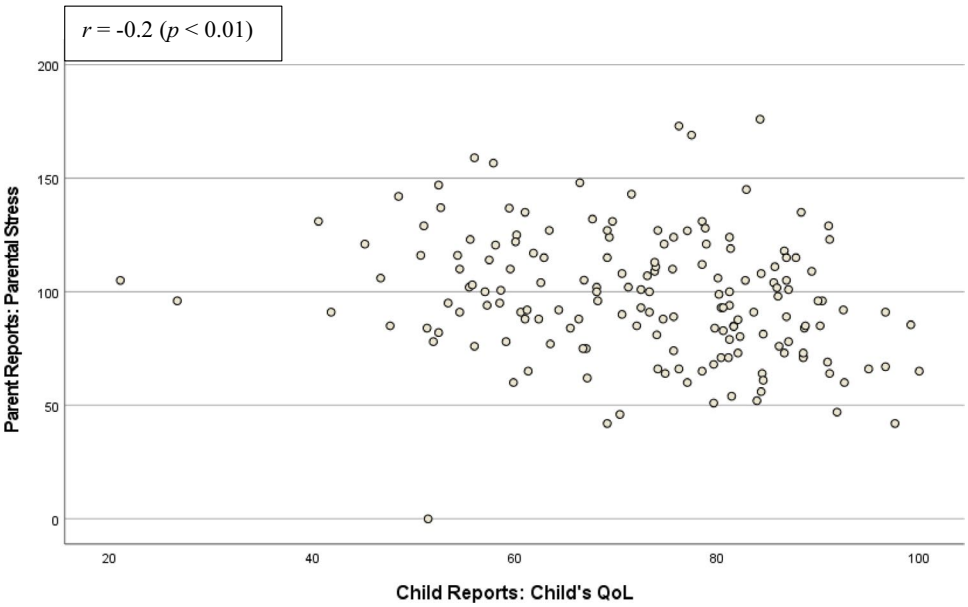

Fig. 3 Pearson's correlations between total scores of child self-reports of PedsQL.™ 4.0 Generic Core Scales and total frequency scores of Pediatric Inventory for Parents ($N = 159$)

N, number; *r*, Pearson's correlation coefficient; *p*, p-value.

present in children with acquired diseases with proteinuria and hypertension ($n = 25$).

Discussion

This multicentric study investigated quality of life (QoL) and illness-related parental stress in a large sample of children with kidney diseases. All patients were divided into 5 kidney disease categories according to the official multidisciplinary care program criteria, prescribed by the Belgian authorities. First, child self-reports showed no differences in QoL between the 5 categories, whereas parent proxy reports demonstrated significant differences in total and physical QoL between all categories. Moreover, parents of transplant patients reported lower QoL in their child in all domains and higher levels of parental stress, compared with parents of children without kidney transplant. Second, child's QoL and parental stress were found to be negatively correlated. Third, the combination of lowest QoL and highest parental stress was most present in transplant patients.

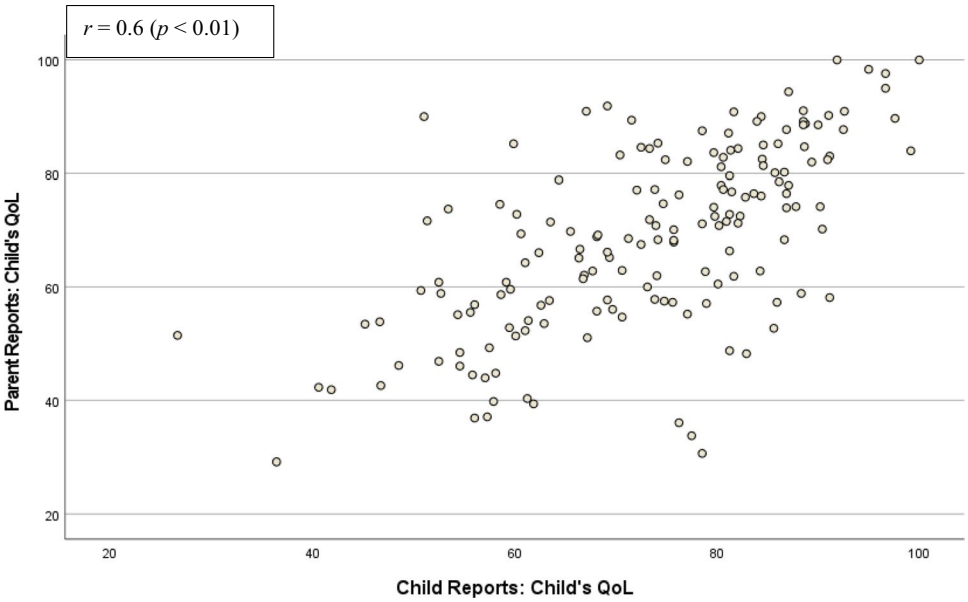

Fig. 4 Pearson's correlations between total scores of child self-reports and parent proxy reports of PedsQL.™ 4.0 Generic Core Scales ($N = 157$)

N, number; *r*, Pearson's correlation coefficient; *p*, p-value.

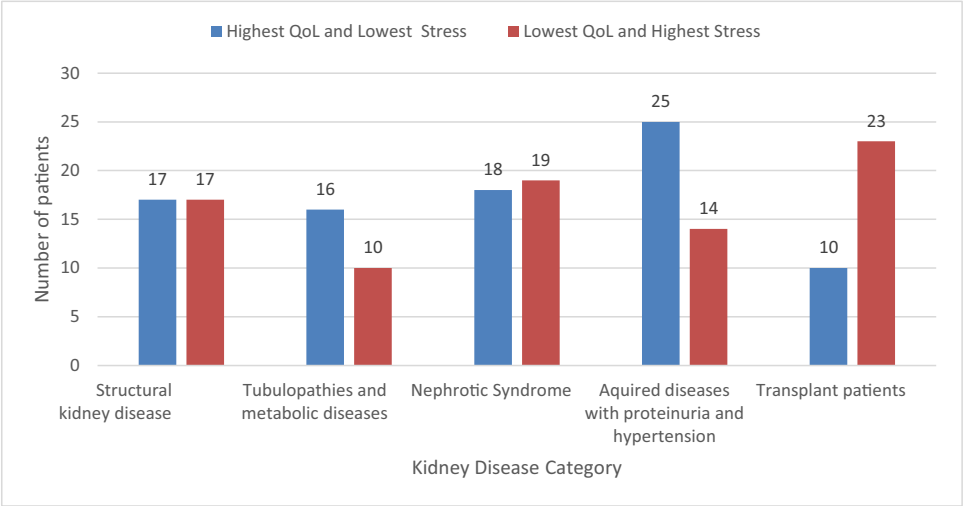

Fig. 5 Highest and lowest levels of child's QoL and parental stress according to parent proxy-reports of PedsQL™ 4.0 Generic Core Scales and Pediatric Inventory for Parents

Parents of transplant patients reported significantly lower QoL in their child, compared with parents of kidney patients without a transplant. However, no significant QoL differences were found in the child self-reports. These results are consistent with an earlier study reporting a lower QoL in transplant children compared with chronic kidney disease (CKD) patients receiving conservative treatment when based on parent proxy reports, but not on child self-reports [4]. Also, Abrao et al. found parents of transplant patients reporting lower QoL in their child compared with parents of children with CKD stages 3–4 and children on dialysis [15]. Similar to QoL, in this study parents of transplant patients reported significantly higher stress compared with parents of non-transplant patients. Moreover, the combination of lowest levels of child's QoL and highest levels of parental stress was most prevalent in the transplant group. This finding is in accordance with earlier studies concluding that even successful kidney transplantation does not necessarily reduce burden as only the nature of concern and difficulties differ [8, 18, 31–33]. Although less intensive than before, parents still have to cope with some dietary restrictions, complex and time-intensive medical treatments, successive outpatient visits or hospitalizations, and the lifelong consequences of the disease [34, 35]. On a daily basis, parents feel a strong sense of responsibility for their child's health and may fear kidney rejection or loss. Parents might experience an enduring insecurity about the child's future [17] and a challenging transition to adulthood [31, 32]. Also, transplantation can lead to parental role disruption and financial stress [17]. Splinter et al. found kidney transplant patients to have

severely impaired QoL equal to children on dialysis [16]. Nevertheless and essential to emphasize, the majority of studies conclude that both patients and parents of patients with a kidney transplant report a better QoL than children on dialysis, which supports the current practice of promoting transplantation as the therapy of choice for children with kidney failure [7, 33, 36, 37]. Also, in this study, duration of dialysis before transplantation was negatively correlated to child's QoL, when based on parent reports.

Lower scores for child's QoL, either reported by the child or the parent, were significantly associated with higher scores for parental stress. This finding is consistent with Falger et al. who found that the QoL of children with CKD is negatively correlated with parental distress [32]. As possible explanations, they hypothesized parents might be more pessimistic about their children's QoL due to an impairment of their own QoL or a higher awareness concerning the impact of their child's disease, for example, regarding their child's emotions, pain, or the long-term outcome. In our study, also, the children's self-reported QoL showed a negative correlation with parental stress. Similarly, Goldstein et al. hypothesized that parental distress might not only affect the parents' but also the children's perceptions of the health and well-being of the child with CKD [2].

In this study, the QoL outcomes of child self-reports and parent proxy reports are almost equal for all kidney disease categories, except for the transplant group where children rate their own QoL higher compared with parents rating them. Differences in the information provided by patient and proxy respondents have been reported in earlier QoL studies with young CKD patients [2, 8, 32, 38, 39], but also in patients with other chronic health conditions or non-clinical groups, which highlights the need to include both child self-reports and parent proxy reports [21, 40–42].

Parents whose children had a shorter kidney disease duration reported more illness-related stress. This finding is consistent with previous studies in pediatric oncology, indicating that distress in parents is initially high at the time of diagnosis with stress decreasing over time, even without intervention [24, 43]. The mean levels of parental stress in our transplant group are considerably higher than those reported in parents of children with other chronic diseases, such as type 1 diabetes [27] or inflammatory bowel diseases [28], but comparable to those reported in parents of cancer patients [24, 25] or heart transplant patients [29]. This higher presence of parental stress could be explained by the constant uncertainty, including fear of rejection and anticipation of what life may be if dialysis is required again due to kidney graft loss. This uncertainty might be less prevalent in other illnesses where there is more clarity about what lies ahead [44]. Also, differences in life expectancy and treatment regimen demands are likely to impact these families in unique ways [14]. These findings may confirm and reinforce the need for screening and evaluating parental stress in this parent group, not only before and throughout but also long after their child's kidney transplant process [17]. A measurement tool specific to parents of children with kidney disease, such as the Paediatric Renal Caregiver Burden Scale, could be considered [45]. Also, future research could further explore the specific domains of illness-related stress so psychological interventions could be more tailored to parents' needs.

The present study has a number of strengths. First, to our knowledge, this is the first study to include a large cohort of different kidney disease categories, ranging from mild CKD stages to transplant patients. In our opinion, analyzing patients divided in these categories contributes to new insights about QoL and parental stress in this population. Second, this multicentric study included a large sample size, which is rather rare for studies with pediatric kidney disease patients and may contribute to the generalizability of these findings. Third, we used children and parents as informants. Exploring QoL in a pediatric population should always include both patient self-reports and parent proxy reports, as the accuracy of only using one type of informant has been questioned in many earlier studies [21, 40–42].

Several important limitations of our study must be acknowledged. First, as prescribed by the official multidisciplinary care program criteria, all patients recruited from the Belgian reference centers for pediatric nephrology were divided in 5 categories. This resulted in a heterogenic study sample with the exclusion of certain kidney diseases and of dialysis patients. It is also important to note that while our study patients were equally distributed over the 5 disease categories, stages 4 and 5 were underrepresented. Second, this study collected a rather small number of sociodemographic and medical variables. Future research should explore possible predictors or mediating factors considering parent and child characteristics, as previous literature has found QoL to be negatively impacted by a child's short stature [46], anemia [34], or by sociodemographic stressors such as being from a non-Western origin [9]. Additionally, more psychosocial variables such as personality traits, resilience, and psychiatric comorbidities could be added as possible mediating or moderating factors. Third, parents and patients with insufficient knowledge of Dutch or French were excluded from the study, which may have biased the sample. Given the increase of non-native speaking families (i.e., refugees and migrants) in all Belgian centers for pediatric nephrology, future studies should make great efforts to also include these families and explore their specific or additional burdens and needs [47]. Finally, the design of the study was cross-sectional, preventing firm conclusions about the directions of the effects between the variables. Longitudinal designs are needed to address this issue.

As we have demonstrated the importance of screening child's QoL and parental stress in a pediatric nephrology population, a multidisciplinary approach should always target both patients and parents. In case of lower QoL or parental stress, Aier et al.

present a psychological management plan, with interventions focusing on the child with CKD (e.g., implementing self-care skills and coping strategies) and their parents (e.g., balancing their responsibilities, increasing parental self-efficacy, and decreasing parental stress) [48]. Moreover, including paramedical disciplines such as a psychologist, a specialized nurse and a social worker seems essential as they can improve the clinical outcomes of children with CKD [49].

In conclusion, this study highlighted the need for a holistic approach for children with kidney diseases and their families. Although kidney transplantation is justifiably perceived as the most positive treatment, we found children after transplantation to be more vulnerable to lower QoL and higher parental stress. This finding indicates the benefits of early identification of psychological needs throughout and after the transplantation process, not only for the child but also for the parent or caregiver. A multidisciplinary care program as organized in the 6 Belgian reference centers for pediatric nephrology can provide psychosocial support for these patients and their families. Further exploration of protective and risk factors influencing a child's QoL and parental stress could optimize these findings for research and clinical practice.

Appendix

Criteria for the kidney disease categories of the multidisciplinary care program for all pediatric nephrology reference centers, as defined by Belgian authorities.

1. Structural kidney diseases: patients with a kidney disease which eventually requires kidney replacement therapy (dialysis and/or transplantation): a hereditary and/or congenital structural kidney disease. From the age of 1 year, children with this disease only belong to this target group if their GFR is less than 30 ml/min per 1.73 m^2; under the age of 1 year, this additional condition in relation to the GFR does not apply.
2. Tubulopathies and metabolic diseases: patients with a kidney disease which eventually requires renal replacement therapy (dialysis and/or transplantation):

   2.1. A metabolic disease

   2.2. A tubulopathy; especially patients suffering from one of the following conditions:
   - Chronic primary tubular acidosis
   - Bartter syndrome
   - Fanconi syndrome
   - Gitelman syndrome
   - Phosphate diabetes
   - Dent's disease
   - Nephrogenic diabetes insipidus
   - Pseudohypoaldosteronism
   - Cystinuria
   - Gordon syndrome

3. Nephrotic syndrome: patients with a severe kidney disease referred to in points 3.1. or 3.2. below, but with a preserved kidney function, which needs treatment and follow-up for life to prevent dialysis or transplantation:

   3.1. A congenital nephrotic syndrome (which is present at birth or which is present before the end of the sixth month of life)

   3.2. A corticoresistent nephrotic syndrome or frequent relapsing, from the third relapse

4. Acquired disease with proteinuria and hypertension: patients with an acquired kidney disease with persistent proteinuria > 500 mg/1.73 m^2/day and/or a hypertension > 95th percentile for age providing regular follow-up and medical treatment for need life.
5. Kidney transplantation: patients who have undergone a kidney transplant and need to be monitored to ensure that the remission period lasts as long as possible.

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Data availability The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval The questionnaires and methodology for this study were approved by the Ethics Committee of the Leuven University Hospital as the central Ethics Committee (Ethics approval number: S61593). All other 5 centers (Ghent University Hospital, Antwerp University Hospital, Queen Fabiola Children's University Hospital Brussels, Saint-Luc Brussels University Hospital, and CHC-MontLégia Health Group Liège) were approved as amendment studies.

Consent to participate A written informed consent was obtained from all parents and children over 12 years of age included in the study.

Conflict of interest The authors declare no competing interests.

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