Kakovost življenja slovenskih otrok in mladih odraslih z redkimi boleznimi ledvic

Health-related Quality of Life in Slovenian Pediatric and Young Adult Patients with Rare Kidney Diseases

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Izvleček

Namen: *Pacienti z redkimi boleznimi ledvic potrebujejo posebno zdravstveno obravnavo in neredko doživljenjsko zdravljenje. Pomemben aspekt je njihova kakovost življenja, na katero vplivajo številni dejavniki. V tej presečni študiji smo nameravali oceniti kakovost življenja otrok in mladih odraslih z redkimi ledvičnimi boleznimi, da bi lahko izboljšali njihovo oskrbo. Članek izhaja iz naše raziskovalne naloge »Kvaliteta življenja otrok z redkimi boleznimi ledvic in njihovo zdravljenje«, ki je 6. 12. 2024 prejela Dekanovo priznanje za študente.*

Metode: *Študija je potekala pod vodstvom Klinike za pediatrijo Univerzitetnega kliničnega centra (UKC) Maribor in je vključila 2–25-letne bolnike z redkimi*

Abstract

Purpose: *Patients with rare kidney diseases require specialized and typically lifelong treatments. Quality of life is an important aspect of a person's well-being, and it is influenced by numerous factors. This cross-sectional study aimed to assess the quality of life of affected children and young adults to guide optimal treatment and enhance care. It is based on our research paper that was awarded the Dean's Recognition for Students on December 6, 2024.*

Methods: *The study included patients aged 2–25 years with rare kidney diseases who were managed in the Department of Pediatrics at the University Clinical Centre Maribor and registered in the European Rare Kidney Disease Registry. The Pediatric Quality of Life Inven-*

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boleznimi ledvic iz registra ERKReg (angl. European Rare Kidney Disease Registry). Udeleženci oziroma njihovi starši so izpolnili standardiziran vprašalnik o kvaliteti življenja otrok (angl. PedsQL). Analizirali smo 69 vprašalnikov otrok in 58 vprašalnikov staršev. Rezultati so predstavljeni z deskriptivnimi metodami. Za določitev razlik v funkcioniranju med starostnimi skupinami smo uporabili Kruskal-Wallisov test in Dunnov post-hoc test z Bonferronijevo korekcijo. Odgovore staršev in otrok smo primerjali s pomočjo t-testa za parne vzorce.

Rezultati: *Otroci so skupno kakovost življenja ocenili z mediano 82,5 (IQR = 17,45), njihovi starši pa s 83,91 (IQR = 17,85), tj. od skupno 100 možnih točk. Mladostniki bolje funkcionirajo na socialnem področju kot mlajši otroci (H = 11,335; p = 0,023). Odgovori staršev se ujemajo z odgovori otrok na fizičnem (t = -0,354; p = 0,725), čustvenem (t = -0,574; p = 0,569), socialnem (t = 0,061; p = 0,951), šolskem (t = -0,271; p = 0,787) in skupnem področju (t = -0,765; p = 0,448).*

Zaključek: *Udeleženci imajo dobro splošno kakovost življenja, kar poudarja pomen dosedanje in prihodnje multidisciplinarne oskrbe ter nadaljnjih intervencij za preprečevanje morebitnega poslabšanja.*

tory questionnaire was sent to the participants and their parents as proxy reports, and 69 patient questionnaires and 58 parent questionnaires were obtained for analysis. Descriptive methods were used to present the results. The Kruskal–Wallis and Dunn's post hoc test with Bonferroni correction were used to determine functioning differences among different age groups, whereas the paired-samples t test was used to compare parent–child responses.

Results: *Patients rated their overall quality of life with a median of 82.5 [interquartile range (IQR) = 17.45], whereas parents rated it with a median of 83.91 (IQR = 17.85), out of 100. Adolescents had better social functioning than young children (H = 11.335; P = 0.023). Parents' reports aligned with those of children [physical (t = −0.354; P = 0.725), emotional (t = −0.574; P = 0.569), social (t = 0.061; p = 0.951), school (t = −0.271; P = 0.787), and total functioning (t = −0.765; P = 0.448)].*

Conclusion: *Participants had good overall functioning, highlighting the importance of multidisciplinary care and the need for further interventions to enhance health and prevent potential deterioration.*

INTRODUCTION

Rare kidney diseases are a heterogeneous group of at least 150 medical conditions characterized by a chronic, progressive, and often degenerative course. Patients with these diseases require specialized medical care with lengthy diagnostic procedures and, in many cases, lifelong treatment (1, 2). These conditions significantly impact the quality of life of patients, making good treatment adherence crucial for achieving optimal health outcomes (3, 4).

Rare kidney diseases negatively influence the physical functioning of children (5, 6). Pediatric patients with these conditions are less physically active than their healthy peers, resulting in poorer physical performance (5, 6). They also lack confidence, skills, and motivation to participate in physical activities (5). Although the connection between these diseases and emotional functioning is well-known, emotional aspects often receive inadequate attention (7). Children with rare kidney diseases are more likely to develop mental health issues, including anxiety, depression, and adjustment disorders, compared with their healthy peers (3). Hence, the focus should be on prevention, early detection, and provision of sufficient psychological support (8–10).

Rare kidney diseases also impair social functioning (10, 11). Affected children often experience limitations in their ability to socialize with peers, engage in sports, and participate in school trips due to frequent medical visits and treatments (10, 11). This leads to smaller social networks and increased isolation, making peer acceptance an even greater challenge for these children (10). Moreover, managing disease

complications (e.g., urinary incontinence) is essential because they can be disruptive, cause discomfort, lower self-esteem, and increase social isolation (10, 12). Finally, these diseases negatively influence neurological development (13). Approximately 20%–25% of children aged less than 5 years with grade 5 chronic kidney disease experience general developmental delays, including difficulties with attention, executive functions, and visual–spatial abilities (13). Previous studies indicated that kidney transplant recipients scored lower in math and reading compared with their healthy peers but performed better than those on dialysis (13, 14).

Health-related quality of life in pediatric patients with rare kidney diseases remains less explored in Slovenia, which motivated us to conduct this study to evaluate the physical, emotional, social, and academic functioning of these patients, along with parental perceptions. We assessed the following hypotheses:

1. The overall quality of life score is less than 75, according to the PedsQL questionnaire.
2. Parents rate their children's quality of life lower than the children themselves.

We hope this study will improve care strategies and enhance the quality of life of pediatric patients with rare kidney diseases.

MATERIAL AND METHODS

Study design, setting, and patient sample

The cross-sectional study was coordinated by the Department of Pediatrics at University Medical Centre (UKC) Maribor, Slovenia, and received ethical approval in November 2023 (15). In December 2023, we acquired a list of 152 patients with rare kidney diseases also included in the European Rare Kidney Disease Registry. All patients met the inclusion criteria: (a) age between 2 and 25 years; (b) diagnosis of rare kidney disease; and (c) mental ability to complete the questionnaire. We contacted the parents or patients directly, explained the background and purpose of the study, and obtained their oral consent. Instructions were also provided. A total of 114 parents responded to the call. Standardized PedsQL 4.0 questionnaires were sent to participating children, young adults, or their parents (16). Each parent received two questionnaires (except for those of toddlers and young adults, who received one). One was for the parents, and the other was for their child. The data were collected from January 2024 to June 2024 (15).

Measures

We used the PedsQL Generic Core Scales version 4.0 in Slovenian translation. It comprised parallel patient self-report and parent proxy-report questionnaires: age 5–7 years for young children, 8–12 years for children, and 13–18 years for adolescents (17). We also used the parent proxy report for toddlers (age 2–4 years) and the self-report for young adults (age 18–25 years). All mentioned questionnaires are freely available for nonfunded academic research, which include those used in our study, on the ePROVIDE Mapi Research Trust website (16). The questionnaires comprise 23 items assessing physical (8 items), emotional (5 items), social (5 items), and school (5 items) functioning of respondents, focusing on the frequency of specific problems in the last month (17). Respondents used a 5-point response scale, whereas younger children used a 3-point scale. Surveys with more than 50% missing responses were considered invalid (18). We used all received questionnaires (69 patient self-reports and 58 parent proxy reports) for analysis (15). The survey items were linearly converted into a 0–100 scale: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0 (5-point scale) or 0 = 100, 2 = 50, and 3 = 0 (3-point scale), where higher scores indicated better functioning (18). Individual categories of scale scores were combined into a total scale score (18).

Outcomes

Primary outcomes included physical functioning, emotional functioning, social functioning, school functioning, and total scale score. Secondary outcomes included parents' responses. Sex, illness duration, and comorbidities were not considered.

Statistical analysis

We used JASP (Jeffreys's Amazing Statistics Program), version 0.18.3, to calculate descriptive statistics and

the Shapiro–Wilk test to assess the normality of distribution. Nominal variables were presented as numbers and percentages (%), and numerical variables as the median and interquartile range (IQR). We used the Kruskal–Wallis test and Dunn's post hoc test with Bonferroni correction to determine differences in quality of life among patients with different age groups. We compared parent–child responses using the paired-samples t test.

Ethical statement

The study was approved by the Committee for Medical Ethics at the University Clinical Centre Maribor (No. UKC-MB-KME-54/23, 30 November 2023). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed in the study.

RESULTS

Sample characteristics

A total of 114 parents consented to participate in our study. Of the 202 questionnaires sent, we received 69 patient self-reports (60.5% response rate) and 58 parent proxy reports (65.9% response rate), all were considered valid for the study. Of the 69 patients, 8 were toddlers (11.6%), 6 young children (8.7%), 21 children (30.4%), 22 adolescents (31.9%), and 12 young adults (17.4%). Of the 58 parents, 6 had young children (10.3%), 25 had children (43.1%), and 27 had adolescents (46.6%).

The distribution of rare kidney disease groups among participants, classified according to the list published on the ERKNet website, is presented in Table 1 (19).

Quality of life across all patients and age groups

The Shapiro–Wilk test indicated an abnormal distribution of individual and total categories of scale scores in the patient group [physical ($W = 0.805$; $P < 0.001$), emotional ($W = 0.944$; $P = 0.004$), social ($W = 0.811$; $P < 0.001$), school ($W = 0.928$; $P < 0.001$), and total functioning ($W = 0.929$; $P < 0.001$)] and the parent group [physical ($W = 0.722$; $P < 0.001$), emotional ($W = 0.902$; $P < 0.001$), social ($W = 0.806$; $P < 0.001$), school ($W = 0.920$; $P = 0.003$), and total functioning ($W = 0.900$; $P < 0.001$)].

The scale score categories and total scale score for all patients and by age group, expressed as the median (IQR), including both patient and parent responses, are shown in Table 2, along with the paired-samples t test results.

Differences in quality of life among different age groups

The Kruskal–Walli's test results showed no significant difference in the quality of physical ($H = 2.413$; $P = 0.660$), emotional ($H = 6.410$; $P = 0.171$), school ($H = 3.413$; $P = 0.491$), and total functioning ($H = 4.453$; $P = 0.348$) based on the age group. However, social functioning did differ based on the age

Table 1. Distribution of rare kidney disease groups among participants

Disease group	Age group				
	Toddlers (n = 8)	Young children (n = 6)	Children (n = 21)	Adolescents (n = 22)	Young adults (n = 12)
Glomerulopathies	/	*n* = 3	*n* = 3	*n* = 6	*n* = 5
Tubulopathies	/	/	*n* = 1	*n* = 1	*n* = 1
Renal or urinary tract malformations	*n* = 7	*n* = 2	*n* = 14	*n* = 9	*n* = 3
Familial cystic renal diseases	*n* = 1	*n* = 1	*n* = 2	*n* = 5	*n* = 3
Thrombotic microangiopathies	/	/	/	*n* = 1	/
Rare causes of hypertension	/	/	*n* = 1	/	/

n, Number of participants.

Table 2. Presentation of the quality of life with median (IQR)

	Patient Self-Report	Parent Proxy-Report	Paired-Sample-T-test			
			t	p	MD	95 CI
5-7 years						
Physical functioning	90.63 (15.63)	98.44 (13.84)	-0.213	0.839	-4.17	-54.4; 46
Emotional functioning	75 (17.5)	72.5 (26.25)	0.117	0.912	1.67	-35.1; 38.4
Social functioning	75 (17.5)	87.5 (28.75)	-1.954	0.108	-16.67	-38.6; 5.3
School functioning	75 (25)	80 (15)	-0.201	0.849	-2.5	-34.5; 29.5
Total functioning	78.59 (6.8)	83.36 (18.71)	-0.589 -	0.582	3.91	-21; 13.2
8-12 years						
Physical functioning	93.75 (15.63)	93.75 (12.5)	-0.207	0.638	-0.89	-9.9; 8.1
Emotional functioning	80 (25)	80 (15)	-0.478	0.638	-2.86	-15.3; 9.6
Social functioning	90 (25)	85 (25)	0.312	0.758	1.73	-9.8; 13.3
School functioning	80 (15)	80 (15)	0.890	0.384	2.86	-3.8; 9.6
Total functioning	86.25 (17.81)	83.44 (12.81)	-0.322	0.751	-0.71	-5.3; 3.9
13-18 years						
Physical functioning	90.63 (17.9)	93.75 (10.94)	-0.176	0.862	-0.95	-12.1; 10.2
Emotional functioning	77.5 (30)	85 (35)	0.472	0.642	-2.96	-16; 10.1
Social functioning	100 (15)	100 (25)	0.582	0.567	3.41	-8.8; 15.6
School functioning	76.25 (42.5)	80 (35)	-0.631	0.535	-4.21	-18.1; 9.6
Total functioning	83.67 (17.75)	83.9 (24.63)	0.423	0.677	-1.1	-6.5; 4.3
Entire sample						
Physical functioning	93.75 (21.87)	93.75 (12.5)	-0.354	0.725	-1.32	-8.8; 6.2
Emotional functioning	70 (30)	80 (28.75)	-0.574	0.951	-2.35	-10.6; 5.9
Social functioning	90 (25)	95 (25)	0.061	0.951	0.23	-7.3; 7.7
School functioning	75 (26.67)	80 (23.75)	-0.271	0.787	-0.97	-8.2; 6.2
Total functioning	82.5 (17.45)	83.91 (17.85)	-0.765	0.448	-1.28	-4.6; 2.1

CI, Confidence interval; MD, mean difference; t, value of the statistical test.

group (H = 11.335; P = 0.023). Dunn's post hoc test with Bonferroni correction revealed better social functioning among adolescents than young children (P = 0.023).

Differences between patient self-report and parent proxy-report

The Shapiro–Wilk test [(physical (W = 0.958; P = 0.079), emotional (W = 0.986; P = 0.812), social (W = 0.984; P = 0.729), school (W = 0.970; P = 0.249), and total functioning (W = 0.984; P = 0.742)) indicated the normal distribution of the differences in responses between patient self-reports and parent proxy-reports. Therefore, the parametric version of the paired-samples t test was used (Table 2). The responses of parents and their children did not differ significantly in any of the examined fields (P > 0.05).

DISCUSSION

Quality of life of the entire sample of patients

Our results suggested that Slovenian children and

young adults with rare kidney diseases reported a good overall quality of life. Patients rated it with a median of 82.5 (IQR = 17.45), whereas their parents rated it at 83.91 (IQR = 17.85). Consequently, we could reject the first hypothesis, which predicted that the overall quality of life score would be less than 75. Our findings were comparable to those of previous studies (20, 21). Minor discrepancies might be attributed to the varying characteristics of the included participants and the varying standards of living across different countries. The positive overall functioning could be attributed to medical advances, including comprehensive healthcare, support in school and social areas, psychosocial support, and other adjustments that help children manage daily challenges (12).

Participants rated physical functioning the highest and emotional functioning the lowest, whereas parents rated social function the highest and emotional the lowest. This was consistent with previous findings, as poor emotional functioning was influenced by numerous factors (3). Differences in how children and their parents perceived the difficulties highlighted various aspects of living with the disease (22). Children might perceive physical functioning as better because they developed coping strategies and accepted disease limitations as normal (22). Additionally, we believe that physical difficulties are more apparent than social ones. This is because children often do not communicate their social struggles, which makes parents underestimate their severity.

Quality of life across different age groups

Young children exhibit poorer social functioning than adolescents, which can be explained in many ways (23). On the one hand, bullying is mentioned as being more prevalent in childhood than in adolescence (24). On the other hand, adolescents are more independent than young children, who are either not yet in or just beginning the phase of secondary socialization (23). The presence of a chronic illness can hinder this process because various impairments negatively impact self-esteem, and, consequently, relationships with peers (3). Moreover, the brain undergoes remodeling during adolescence; hence, neural plasticity may facilitate the development of social cognitive skills (25).

Comparison of patient self-report and parent proxy-report

Information provided by proxies, most often parents, does not always align with the information reported by the patients themselves (26). Discrepancies, to some extent, are not surprising because a child's perception of quality of life often differs from that of their parents (26). Eiser and Morse found that the greatest differences in responses appeared in the areas of emotional and social functioning, whereas the highest agreement was observed in physical functioning (27). However, other researchers believe that this is not always the case (28, 29). Therefore, our results are noteworthy because we did not find significant differences between the responses, contradicting our second hypothesis. Harmer et al. also discovered a similarly strong correlation, possibly due to the relatively small sample size (30).

Parents of young children believed that their children experienced the fewest difficulties with emotional functioning, whereas the children perceived school functioning as their greatest challenge. This nonsignificant discrepancy might be due to the children's limited awareness of the complexity of their emotional problems (25).

The responses of children aged 8–12 years and adolescents aligned with those of their parents. This high level of agreement between adolescents and parents contradicted previous findings, including the one by Nap-van der Vlist et al. (31).

Limitations and future research

A significant limitation of our study was the variability of rare kidney diseases among participants, which differed in clinical presentation, severity, and prognosis. Besides chronic illness, numerous other factors, not considered in our study, affect the quality of life of patients. Therefore, future research should account for multifactorial influences. The questionnaires were sent to the participants, making it challenging to strictly adhere to the instructions. It is possible that parents completed or at least influenced the responses of their children. We suggest administering the questionnaire during a follow-up visit for future studies, although it may require additional time and effort from healthcare workers.

CONCLUSIONS

The participants rated their quality of life at 82.5 out of 100 on the PedsQL questionnaire, indicating good overall functioning. The study reported no significant differences in physical, emotional, school, and overall functioning across different age groups. However, social functioning was better among adolescents compared with young children. Additionally, parents' reports aligned with those of their children. The study also highlighted the need for increased therapeutic engagement in emotional support and treatment. Finally, it reaffirmed the value of multidisciplinary care, treatment, and monitoring of these patients.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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