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Assessment of Disease Knowledge Level of the Caregivers of Pediatric Patients With Chronic Kidney Disease

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Abstract

Background

Chronic kidney disease (CKD), characterized by long-term decline in kidney function. Early detection and treatment may be associated with a delay in the progression of the disease. Increased awareness and knowledge on the disease carries great importance. In this study, CKD knowledge level of the caregivers of pediatric CKD patients was assessed.

Methods

Caregivers of pediatric patients aged 1–21 years with stage 2–5 CKD who had not yet started kidney replacement therapy (KRT), and had at least 1-year follow-up were recruited. CKD knowledge levels were assessed using a questionnaire developed based on a review of the literature. Demographic features potentially associated with knowledge level, the impact of knowledge on the patients' prognosis and disease progression were investigated.

Results

47 pediatric CKD patients, with a mean age of 14 ± 3.9 years, along with their caregivers were included. Average follow-up duration was 6.5 years. Mean eGFR at CKD diagnosis was 58.3 mL/min/1.73 m² (Stage 3a) and mean eGFR during study period was 39.5 mL/min/1.73 m² (Stage 3b). Mean score was 64.9 out of 100 on the questionnaire. Caregivers of patients with early-stage CKD (stages 2–3) had higher educational levels (p = 0.048), caregivers of patients diagnosed at advanced-stage CKD and caregivers with healthcare workers in their family demonstrated higher CKD knowledge levels (p = 0.048 and p = 0.020, respectively). Higher caregiver CKD knowledge levels were associated with reduced school absenteeism (p = 0.020) and better school performance (p = 0.008).

Conclusion

We believe that targeted educational interventions to improve caregivers' knowledge may contribute to better quality of patients life.

INTRODUCTION

Chronic kidney disease (CKD) is irreversible and progressive kidney damage that leads to a long-term decline in kidney function[1]. However, as the disease may manifest with subtle clinical findings or even remain asymptomatic in the early stages[2] and due to the physiological differences in glomerular filtration rate (GFR) during the early years of life, diagnosing CKD in the pediatric population can be challenging. This increases the risk of missed diagnoses, delayed treatment, and inappropriate clinical

management [3]. Population-based studies suggest that up to 1% of children may suffer from CKD. Advanced CKD stages at the time of diagnosis are associated with more rapid loss of residual kidney function [3]. Based on the data from the North American Pediatric Renal Trials and Collaborative Studies (NAPRTCS), the progression rate to stege 5 CKD in children with stage 2–4 CKD is 17.3% per year and 39% within three years, with an average time to stage 5 CKD of 4.5 years [4]. As the disease progresses, CKD complications become evident, including cardiovascular disease, growth retardation, and cognitive impairments[5]. Children with stage 5 CKD undergoing dialysis have a mortality rate of 30 to 150 times higher than the general pediatric population. The life expectancy of a child on dialysis is approximately 50 years shorter compared to a healthy child[6]. Beyond its impact on morbidity and mortality, pediatric CKD poses a considerable economic burden for countries[7].

Good knowledge level of CKD and early diagnosis are crucial in slowing disease progression in its early stages and improving outcomes[8]. Several studies have evaluated CKD awareness among the general population, healthcare providers, adult patients, and caregivers, consistently demonstrating limited disease-related knowledge [10]. However, no standardized tools exist to measure CKD knowledge, and to our knowledge, no studies have specifically assessed knowledge related to pediatric CKD. Therefore, this study aimed to evaluate CKD knowledge levels among caregivers of pediatric CKD patients, identify sociodemographic factors associated with insufficient knowledge, determine knowledge gaps, and examine associations between caregiver knowledge and disease progression as well as long-term complications.

MATERIALS AND METHODS

Study Group and Exclusion Criteria

This face-to-face survey was conducted with caregivers of CKD patients aged 1 to 21 years, followed for at least one year at the Pediatric Nephrology Clinic of Gazi University Hospital. Primary caregivers of patients with stage 2, 3a, 3b, 4, and non-dialysis dependent stage 5 CKD KRT were enrolled in the study between March and July 2024. Those who declined participation, caregivers of patients diagnosed with CKD less than a year, and caregivers of patients receiving KRT were excluded from the study. Informed consent was obtained from the participants.

Data Collection

Our study includes a two-part questionnaire for the patients' caregivers, which developed by the study team based on a thorough literature review. The first section consisted of 38 questions which investigated the demographic data of patients and their caregivers. In this part, information about the primary caregiver such as educational level, monthly income and occupation were collected. The caregivers were questioned about their information sources about the disease, which healthcare staff evaluated them during clinic visits whether they received sufficient information. Data on the family

structure as well as whether there were other family members with CKD, presence of family members on dialysis, children with other chronic illnesses, and presence of a healthcare professional in the family were noted. Additionally, concerning the CKD patients, the duration of CKD follow-up, treatment centers, frequency of check-ups, number of medications used, involvement with other specialties, hospital admissions due to the disease, school attendance status, number of days missed from school and level of academic performance were recorded.

The second part of the study includes 46 self-developed questions aimed at evaluating the level of knowledge caregivers have about CKD. The questions were categorized under seven key themes: 'Kidney Functions', 'General Information about CKD', 'Causes of CKD', 'Symptoms and Signs of CKD', 'Long-Term Complications of CKD', 'CKD Monitoring and Treatment', and 'CKD Diet'. In this form, the first 38 questions consisted of specific statements with multiple-choice answers: 'true', 'false', and 'I don't know'. Each correctly answered statement was awarded 2 points, while incorrect or 'I don't know' responses received 0 points. The next 5 questions were open-ended and designed to assess the caregiver's self-reported knowledge on specific topics. These questions offered the options 'yes', 'partially', and 'no', which were scored as 2,1,0, respectively. The final 4 questions were multiple-answer questions, where more than one option could be selected. Each correctly selected (or correctly unselected) item was scored as 0.5 points. The total maximum score was 100. This questionnaire is given in Supplement 1.

Apart from the questionnaire applied, patient files were overviewed and information about CKD stage at diagnosis, prescribed medications with dosages, follow-up duration, presence of comorbidities, involvement with other specialties, underlying cause of CKD, current CKD stage, and serum creatinine levels were collected.

The patients with stage 2, 3a, and 3b CKD were categorized as having early-stage disease, and those with stage 4 or 5 CKD were categorized as having advanced-stage disease [11]. In addition to the estimated GFR (eGFR) value at the time of diagnosis, eGFR values measured during outpatient follow-ups every six months over the past two years, as well as the last eGFR values, were collected. A decline of more than 25% in eGFR over the two-year follow-up period, a resultant progression in CKD stage, was considered as disease progression.

Data analysis

The collected data were analyzed using the IBM SPSS Statistics software package (Version 27.0). Descriptive statistics were presented as number, percentage, mean ± standard deviation (SD), minimum, maximum, median, and interquartile range (Q1–Q3). For the comparison of categorical variables, Chi-square and Fisher's Exact tests were used. Since continuous variables were not normally distributed, the Mann–Whitney U test and Kruskal–Wallis test were applied for group comparisons. Pearson and Spearman correlation analyses were used to examine relationships between continuous variables. A p-value of ≤ 0.05 was considered statistically significant.

RESULTS

The study included 47 pediatric CKD patients aged between 1.5 and 21 years and their primary caregivers. The mean age of the patients was 14.0 ± 3.9 years and 31 (66%) patients were males. The mean age of the caregivers was 41.5 years and the majority were mothers (n = 35, 74.5%). Most families (59.6%, n = 28) were of middle income. Nine patients (19.1%) had a sibling with a chronic illness, mostly CKD (88.8%, n = 8). Twelve patients (25.5%) had another relative diagnosed with CKD, five of whom (41.6%) were receiving dialysis. 15 patients (31.9%) had a family member working in healthcare (e.g. physician, nurse, etc.).

The primary cause of CKD in the patient group was congenital anomalies of the kidney and urinary tract (CAKUT), accounting for 48.9% (n = 23) of cases. Average follow-up duration was 6.5 years and majority of the cases (74.5%, n = 35) had been followed in our clinic for more than 5 years. At the time of CKD diagnosis, mean eGFR was 58.3 mL/min/1.73 m², consistent with stage 3a CKD. During the study period, the mean eGFR decreased to 39.5 mL/min/1.73 m², corresponding to stage 3b CKD. At this time, 30 patients (63.8%) were classified as having early-stage CKD (stage 2-3a-3b CKD), while 17 patients (36.2%) were in advanced stages (stage 4–5 CKD).

Approximately half of the patients (45.8%, n = 22) attended outpatient follow-ups once a month, whereas 4 patients (8.3%) had more than one outpatient visit per month. The average number of medications used per patient was 4.5, and 16 patients (34%) were taking more than five medications. Comorbid conditions were identified in 15 patients (31.9%), with neurological disorders being the most frequent (21.3%, n = 10). 39 patients (83%) were also being followed by other departments, most commonly pediatric urology (40.4%, n = 19).

46 patients (97.8%) were at the school age, and among them, 5 patients (10.8%) were not attending school. 33 patients within the school-age (71.8%) were enrolled in formal school education. 19 patients (41.4%) had less than 10 days of school absenteeism in the past year, and approximately half (45.9%, n = 21) achieved academic performance above average. All the demographic and clinical characteristics of the study group are shown in Table 1.

Table 1
Demographic and Clinical Characteristics of the Study Group

Variables	**n**	**% / Mean ± SD (min–max)**
Patient age (years)	47	14.0 ± 3.9 (1.7–20.0)
Caregiver age (years)	47	41.5 6.7 (28.0–54.0)
Duration of outpatient follow up (years)	47	6.5 4.9 (1–17)
Patent gender (Males)	31	66.0
Primary caregiver	35	74.5
Mother	11	23.4
Father	1	2.1
Other		
Presence of consanguinity	18	38.3
Caregiver educational level	15	31.9
Primary school	7	14.9
Secondary school	18	38.3
High school	7	14.9
University/Postgraduate		
Monthly income	14	29.8
Low	28	59.6
Middle	5	10.6
High		
Family structure	39	83.0
Nuclear family	7	14.9
Extended family	1	2.1
Single parent		
Presence of another child with chronic disease in the family	9	19.1
Presence of sibling with CKD	8	17.0
Presence of relatives with CKD	12	25.5
Presence of relatives receiving dialysis	5	10.6

n: number of participants, %: percentage, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease, CAKUT: congenital anomalies of the kidney and urinary tract

Variables	n	% / Mean ± SD (min–max)
Presence of healthcare worker in the family	15	31.9
CKD etiology	23	48.9
CAKUT	11	23.5
Hereditary diseases	11	23.5
Cystic diseases	2	4.1
Other		
CKD stages (mL/min/1.73 m²)	47	58.3 ± 23.1
At diagnosis	47	39.5 ± 22.2
At the time of the study		
Follow-up duration	8	17
1–2 years	4	8.5
2–5 years	35	74.5
>5 years		
Hospitalizations	11	23.4
None	12	25.5
1–2 total	5	10.6
3–5 total	4	8.5
6–10 total	15	31.9
>10		
Number of medications used	17	36.2
1–2	14	29.8
3–5	16	34.0
>5		
Follow-up frequency	3	6.3
Every 6 months	17	35.4
Every 3 months	22	45.8
Once per month	4	8.3

n: number of participants, %: percentage, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease, CAKUT: congenital anomalies of the kidney and urinary tract

Variables	n	% / Mean ± SD (min–max)
More than once per month	1	2.1
Irregular follow-up intervals		
Presence of comorbidities	15	31.9
Neurologic disorders	10	21.3
Anorectal/urogenital problems	4	8.5
Syndromic conditions	3	6.4
Presence of previous follow-up at another center	10	27
Presence of follow-up in another department	39	83
Pediatric urology	19	40.4
Pediatric cardiology	10	21.3
Pediatric surgery	7	14.9
Dietitian	6	12.8
School attendance in school age patients (n = 46)	33	71.8
Regular school attendance	3	6.6
Private education	5	10.8
Online education	5	10.8
No attendance		

n: number of participants, %: percentage, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease, CAKUT: congenital anomalies of the kidney and urinary tract

In our study, half of the patients' caregivers (49%, n = 23) reported being evaluated by a pediatrician/pediatric nephrologist during outpatient visits, 7 caregivers (14.9%) by an attending physician, and 16 (34%) by both pediatrician/pediatric nephrologist and an attending physician together, while 1 caregiver (2.1%) was unsure who evaluated them. During these visits, 20 caregivers (42.6%) stated that they were adequately informed, but only 10 (21.3%) believed they had sufficient knowledge about CKD. The majority of caregivers (91.5%, n = 43) indicated that they received information about CKD primarily from doctors, while 23 (48.9%) also cited the internet and 8 (17%) social media as additional sources of information.

The average score of caregivers on the knowledge survey was 64.9 out of 100. Notably, 44.6% of participants (n = 21) scored below the average, and among these, the majority (66.6%, n = 14) had children with early-stage CKD. The average knowledge score of caregivers of patients with stage 2 CKD was 52.9 (n = 10), while caregivers of patients with stage 5 CKD scored an average of 78.1 (n = 7). Except for those in stage 4, it was observed that caregivers' knowledge level increased with advancing CKD

stage. Subgroup analysis of the knowledge level survey results showed that caregivers correctly answered an average of 19.8 out of 29 questions (68.4%) concerning CKD monitoring and treatment (best scores), whereas 4.1 out of 7 questions (58.0%) related to kidney functions and 2.3 out of 4 questions (58%) about long-term complications of CKD (worst scores) (Table 2).

Table 2
Disease knowledge level of the caregivers according to CKD stages and their scores and correct answers

	Caregivers (n = 47)				
	CKD stage				
	2	**3a**	**3b**	**4**	**5**
CKD knowledge total score, n (%)	52.9 ± 21.8 (20.5–76.0)	63.3 ± 11.1 (49.5–79.0)	72.45 ± 10.1 (59.0–95.0)	60.7 ± 14.8 (38.5–87.0)	78.1 ± 13.4 (56.5–99.0)
Below average	6 (60.0)	6 (66.7)	2 (18.2)	6 (60.0)	1 (14.3)
Above average	4 (40.0)	3 (33.3)	9 (81.8)	4 (40.0)	6 (85.7)
	Early stage		**Advanced stage**		
Below average	14 (46.7)		7 (41.2)		
Above average	16 (53.3)		10 (58.8)		
	True answers/Total answers **Mean ± SD (min-max)**		**Mean score** **Mean ± SD (min-max) / Maximum possible score**		**Correct answer percentile** **Mean ± SD (min-max)**
Kidney functions	4.1 ± 1.4 (1.0–7.0) /7		8.1 ± 2.8 (2.0–14.0) /14		58.0 ± 20.0 (14.3–100)
CKD- General information	3.2 ± 1.3 (0.0–5.0) /5		6.4 ± 2.7 (0.0–10.0) /10		63.8 ± 26.6 (0-100)
CKD- Symptoms	4.7 ± 1.5 (2.0–7.0) /7		9.4 ± 3.1 (4.0–14.0) /14		67.5 ± 22.0 (28.5–100)
CKD- Long-term complications	2.3 ± 1.5 (0.0–4.0) /4		4.8 ± 2.9 (0.0–8.0) /8		58.0 ± 36.9 (0–10)
CKD- Monitoring and treatment	19.8 ± 4.4 (10.0–28.0) /29		23.8 ± 6.1 (9.5–33.5) /34		68.4 ± 15.2 (34.5–96.6)
CKD – Diet	10.8 ± 3.4 (2.0–17.0) /18		11.1 ± 3.8 (1.0-17.5) /18		60.5 ± 18.5 (11.1–94.4)
CKD- Etiology	0.6 ± 0.5 (0.0–1.0) /1		1.2 ± 1.0 (0.0–2.0) /2		59.6 ± 49.7 (0.0-100.0)
CKD knowledge total score, mean ± SD (min-	64.9 ± 16.7 (20.5–99.0)				

n: number of participants, %: percentage, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease

	Caregivers (n = 47)				
	CKD stage				
	2	3a	3b	4	5
max)					

n: number of participants, %: percentage, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease

Regarding CKD knowledge domain, almost all of the caregivers (95.7%, n = 45) knew that the kidney removes excess water from the body, and 83% (n = 39) knew that it cleans harmful substances from the blood. However, 17.0% (n = 8) of the caregivers believed that the kidney is the main organ regulating blood sugar. Approximately half of the caregivers (46.8%, n = 22) were aware that CKD is an irreversible disease. However, overall 21.3% (n = 10) did not know that CKD is a progressive disease and is classified into stages. Additionally, 17% (n = 8) of caregivers were unaware that medical treatments can slow the progression of CKD. Moreover, 14.9% (n = 7) of participants believed that herbal treatments could slow CKD progression. 57.5% (n = 27) of the caregivers knew that CKD may not present with symptoms and only 66% (n = 31) of them correctly stated that hyperphosphatemia can be of critical importance for CKD patients.

40.4% (n = 19) of caregivers did not know the etiology of their patient's disease. 53.2% (n = 25) and 57.4% (n = 27) of caregivers knew their patient's CKD stage and latest serum creatinine value, respectively. While 91.5% (n = 43) of caregivers stated they knew the names and dosages of the medications their patients were taking, the actual proportion who correctly knew these details was lower at 83% (n = 39). Additionally, 80.9% (n = 38) claimed to know the purposes of the medications, but only 34% (n = 16) truly understood their uses. Furthermore, 25.6% (n = 12) stated they were aware of drugs that should be avoided, but only 21.2% (n = 10) actually knew which medications should be avoided. Answers of caregivers are shown in Supplement 2 and 3.

When factors affecting the CKD knowledge level within the patient group were examined, although not statistically significant, caregivers of patients with advanced-stage CKD (p = 0.363), those having another child with CKD under follow-up (p = 0.104), and caregivers with relatives who have CKD (p = 0.608) had higher CKD knowledge scores compared to others. Similarly, higher educational level of the caregiver and increased family income level were associated with higher CKD knowledge scores, but these differences were not statistically significant (p = 0.077 and p = 0.255, respectively). However, children of the caregivers with higher scores had significantly more regular school attendance and better academic success compared to others (**p = 0.020** and **p = 0.008**, respectively, Table 3).

Table 3
Factors affecting the CKD knowledge level of the caregivers

Stage	CKD Knowledge Score		p
	Mean ± SD	(Min-Max)	
Early (n = 30)	63.2 ± 16.9	20.5–95.0	0.363
Late (n = 17)	67.9 ± 16.4	38.5–99.0	
Presence of a healthcare worker in the family			
Yes (n = 15)	71.0 ± 15.7	38.5–99.0	0.085
No (n = 32)	62.0 ± 16.6	20.5–87.0	
Presence of a sibling with CKD			
Yes (n = 8)	73.6 ± 16.0	53.0–99.0	0.104
No (n = 39)	63.1 ± 16.5	20.5–87.0	
Presence of another chronically ill child in the family			
Yes (n = 9)	73.3 ± 15.0	53.0–99.0	0.093
No (n = 38)	62.9 ± 16.6	20.5–87.0	
Family member with CKD			
Yes (n = 12)	67.0 ± 17.7	38.5–99.0	0.608
No (n = 35)	64.1 ± 16.6	20.5–87.0	
Presence of comorbidities in the patient			
Yes (n = 15)	63.0 ± 13.4	50.5–72.0	0.218
No (n = 32)	69.3 ± 17.1	57.0-75.9	
Educational level of the caregivers			
Primary school graduate (n = 15)	57.8 ± 16.4	20.5–87.0	0.077
Middle school graduate (n = 7)	60.5 ± 19.4	22.0–76.0	
High school graduate (n = 18)	68.4 ± 13.7	37.5–86.5	
University/Postgraduate (n = 7)	75.4 ± 17.1	53.0–99.0	
Household income			
Low (n = 13)	61.8 ± 21.4	20.5–87.0	0.255

n: number of participants, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease

Stage	CKD Knowledge Score		p
	Mean ± SD	(Min-Max)	
Medium (n = 28)	64.4 ± 12.7	37.5–83.5	
High (n = 5)	76.1 ± 20.8	49.5–99.0	
Number of hospitalizations of patient			
None	67.7 ± 20.5	22.0–99.0	0.916
1–2	64.0 ± 17.5	37.5–83.5	
3–5	64.7 ± 18.2	44.5–86.5	
6–10	69.5 ± 5.8	62.5–74.5	
>10	62.3 ± 16.0	20.5–87.0	
School absenteeism of patient*			
<10 days/year (n = 19)	72.3 ± 14.8	37.5–99.0	**0.020**
10–30 days/year (n = 11)	60.5 ± 20.6	20.5–87.0	
>30 days/year (n = 11)	57.0 ± 14.5	22.0-74.5	
Academic success of patient*			
Above class average (n = 21)	70.7 ± 17.9	20.5–99.0	**0.008**
Average (n = 16)	63.1 ± 12.6	38.5–87.0	
Below class average (n = 4)	42.6 ± 15.1	22.0-56.5	
Do you think you have sufficient knowledge about CKD?			
Yes (n = 10)	73.5 ± 17.9	44.5–99.0	0.188
No (n = 5)	61.6 ± 13.8	49.5–83.0	
Partially (n = 32)	62.7 ± 16.3	20.5–87.0	
Do you think you have been adequately informed about CKD?			
Yes (n = 20)	65.7 ± 20.3	20.5–99.0	0.949
No (n = 7)	63.5 ± 11.8	53.0–87.0	
Partially (n = 20)	64.5 ± 14.7	22.0–83.0	

n: number of participants, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease

Although not statistically significant, caregivers with above-average scores appeared to have a higher level of education (p = 0.169). Socioeconomic analysis showed that only 4.7% (n = 1) of households of patients with below-average scores reported high income, compared to 15.3% (n = 4) among households of patients with above-average scores (p = 0.456). Among the caregivers who scored above average, children's school attendance and academic performance were found to be significantly higher **(p = 0.013, p = 0.008)**. It was also found that caregivers with a healthcare professional in the family were significantly more likely to score above average **(p = 0.020)**. When comparing participants who scored below and above average, no statistically significant differences were found regarding the presence of comorbidities in the patient, household income, presence of CKD in the family, or having a family member receiving dialysis (p = 0.414, p = 0.456, p = 0.668, and p = 0.466, respectively, Table 4).

Table 4
Comparison of the caregivers with below and above-average scores

	CKD Knowledge Score		p
	Below Average (n = 21)	**Above Average (n = 26)**	
Caregiver age (mean ± SD, min–max)	41.3 ± 6.9 (28.0–53.0)	41.7 ± 6.7 (30.0–54.0)	0.864
eGFR decline per year (mean ± SD, min–max)	5.0 ± 2.8 (0.4–9.3)	6.2 8.6 (0.0–41.0)	0.392
Household number of people (mean ± SD, min–max)	4.4 ± 1.1 (3.0–7.0)	4.7 ± 1.1 (3.0–9.0)	0.514
CKD follow-up duration (years, mean ± SD, min–max)	6.7 ± 5.1 (1.0–15.0)	6.4 ± 4.8 (1.2–17.0)	0.906
Educational level of caregivers			
Primary school graduate (n = 15)	10 (66.7)	5 (33.3)	0.169
Middle school graduate (n = 7)	3 (42.9)	4 (57.1)	
High school graduate (n = 18)	5 (27.8)	13 (72.2)	
University/Postgraduate (n = 7)	3 (42.9)	4 (57.1)	
Household income			
Low (n = 13)	6 (62.9)	8 (57.1)	0.456
Middle (n = 28)	14 (50.0)	14 (50.0)	
High (n = 5)	1 (20.0)	4 (80.0)	
Number of hospitalizations			
None	4 (36.4)	7 (63.6)	0.753
1–2	5 (41.7)	7 (58.3)	
3–5	3 (60.0)	2 (40.0)	
6–10	1 (25.0)	3 (75.0)	
> 10	8 (53.3)	7 (46.7)	
School attendance of the patient**			
< 10 days/year (n = 19)	4 (21.1)	15 (78.9)	**0.013**
10–30 days/year (n = 11)	6 (54.5)	5 (45.5)	

Abbreviations: n: number of participants, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease

	CKD Knowledge Score		p
	Below Average (n = 21)	**Above Average (n = 26)**	
> 30 days/year (n = 11)	8 (72.7)	3 (27.3)	
Academic success of patient**			**0.008**
Above class average (n = 21)	5 (23.8)	16 (76.2)	
Class average (n = 16)	9 (56.3)	7 (43.8)	
Below class average (n = 4)	4 (100.0)	0 (0.0)	
Presence of a another family member with CKD, n (%)			
No	15 (42.9)	20 (57.1)	0.668
Yes	6 (50.0)	6 (50.0)	
Presence of a family member on dialysis, n (%)			
No	18 (42.9)	24 (57.1)	0.466
Yes	3 (60.0)	2 (40.0)	
Presence of a healthcare worker in the family			
No	18 (56.3)	14 (43.8)	**0.020**
Yes	3 (20.0)	12 (80.0)	
Presence of another chronically ill child in the family, n (%)			
No	18 (47.4)	20 (52.6)	0.446
Yes	3 (33.3)	6 (66.7)	
Follow-up frequency, n (%)			
Every 6 months	0 (0.0)	3 (100.0)	0.313
Every 3 months	9 (52.9)	8 (47.1)	
Monthly	10 (45.5)	12 (54.5)	
More than once a month	1 (25.0)	3 (75.0)	
Not attending regularly	1 (100.0)	0 (0.0)	
Comorbidity in the patient, n (%)			

Abbreviations: n: number of participants, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease

	CKD Knowledge Score		p
	Below Average (n = 21)	Above Average (n = 26)	
No	13 (40.6)	19 (59.4)	0.414
Yes	8 (53.3)	7 (46.7)	

Abbreviations: n: number of participants, SD: standard deviation, min: minimum, max: maximum, CKD: chronic kidney disease

In our study, no progression of CKD was observed in 66% of the patients (n = 31) over the past two years, while progression was noted in 34% (n = 16). As expected, the annual eGFR decline rate was significantly higher in the group with progression ($p < 0.001$). When comparing the groups with and without progression, no statistically significant differences were found in terms of CKD knowledge level, caregiver educational level, socioeconomic status, presence of another chronically ill child in the family, number of hospitalizations, school attendance, or academic performance ($p = 0.472$, $p = 0.493$, $p = 0.464$, $p = 0.952$, p 0.873, $p = 0.718$, and $p = 0.667$, respectively).

The educational level of caregivers of patients with early-stage CKD at the study period was significantly higher compared to those of patients with late-stage CKD **($p = 0.048$)**. Although not statistically significant, as the stage of CKD increased in patients, the patients' school attendance and academic performance also tended to decline ($p = 0.108$ and $p = 0.220$, respectively). As expected, the frequency of outpatient clinic visits was significantly higher in patients with advanced-stage CKD compared to those with early-stage CKD **($p = 0.011$)**. It was observed that 88.2% (n = 15) of late-stage CKD patients attended follow-up appointments at least once a month (Table 5).

Table 5
Comparison of the caregivers in terms of CKD stages at the time of study

	CKD Stage		p
	Early (n = 30)	**Advanced (n = 17)**	
Educational level of caregivers			
Primary school graduate (n = 15)	6 (40.0)	9 (60.0)	**0.048**
Middle school graduate (n = 7)	7 (100.0)	0 (0.0)	
High school graduate (n = 18)	12 (66.7)	6 (33.3)	
University/Postgraduate (n = 7)	5 (71.4)	2 (28.6)	
Number of hospitalizations			
None	9 (81.8)	2 (18.2)	0.442
1–2	8 (66.7)	4 (33.3)	
3–5	2 (40.0)	3 (60.0)	
6–10	3 (75.0)	1 (25.0)	
> 10	8 (53.3)	7 (46.7)	
Patients school attendance			
< 10 days/year (n = 19)	14 (73.7)	5 (26.3)	0.108
10–30 days/year (n = 11)	8 (72.7)	3 (27.3)	
> 30 days/year (n = 11)	4 (36.4)	7 (63.6)	
Patients academic success			
Above average (n = 21)	16 (76.2)	5 (23.8)	0.220
At class average (n = 16)	8 (50.0)	8 (50.0)	
Below class average (n = 4)	2 (50.0)	2 (50.0)	
Follow up frequency n (%)			
Every 6 months	2 (66.7)	1 (33.3)	**0.011**
Every 3 months	16 (94.1)	1 (5.9)	
Monthly	10 (45.5)	12 (54.5)	
More than once a month	1 (25.0)	3 (75.0)	

Abbreviations: n: number of participants, %: percentage, CKD: chronic kidney disease

	CKD Stage		p
	Early (n = 30)	**Advanced (n = 17)**	
Educational level of caregivers			
Not attending regularly	1 (100.0)	0 (0.0)	
Total CKD knowledge score, mean ± SD	63.2 ± 16.9	67.9 ± 16.4	0.363
Abbreviations: n: number of participants, %: percentage, CKD: chronic kidney disease			

When comparing the study groups based on the CKD stage at the time of diagnosis, no statistically significant differences were observed between patients diagnosed at early versus advanced stages in terms of caregiver educational level and socioeconomic status (p = 0.591 and p = 0.779, respectively). However, caregivers of patients diagnosed at an advanced stage had significantly higher knowledge scores related to CKD symptoms, long-term complications of CKD, CKD diet, and total CKD knowledge compared to caregivers of patients diagnosed at the early stage **(p = 0.012, p = 0.044, p < 0.01, and p = 0.026**, Table 6**)**.

Table 6
Comparison of caregivers in terms of CKD stages at diagnosis

	CKD Stage at the Time of Diagnosis		p
	Early (n = 39)	**Advanced (n = 8)**	
Educational level of caregivers, n (%)			
Primary school graduate	12 (80.0)	3 (20.0)	0.591
Middle school graduate	7 (100.0)	0 (0.0)	
High school graduate	14 (77.8)	4 (22.2)	
University/Postgraduate	6 (85.7)	1 (14.3)	
Household income, n (%)			
Low	12 (85.7)	2 (14.3)	0.332
Middle	24 (85.7)	4 (14.3)	
High	3 (60.0)	2 (40.0)	
Kidney function score	8.0 (6.0–10.0)	9.0 (6.5–12.0)	0.182
CKD-General knowledge score	8.0 (4.0–8.0)	6.0 (4.0–9.0)	0.561
CKD- Symptoms score	10.0 (6.0–12.0)	12.0 (10.5–14.0)	**0.012**
CKD – Long-term complications score	4.0 (2.0–8.0)	8.0 (4.5-8.0)	**0.044**
CKD – Monitoring and treatment score	23.5 (19.5–28.0)	26.3 (25.1–29.8)	0.132
CKD – Diet score	11.5 (7.0-13.5)	14.5 (13.3–15.4)	**< 0.01**
CKD – Etiology score	2.0 (0.0–2.0)	2.0 (0.5-2.0)	0.427
Total CKD Knowledge score	65.5 (50.5–74.5)	76.0 (65.8–85.7)	**0.026**

Abbreviations: n: number of participants, %: percentage, CKD: chronic kidney disease

DISCUSSION

This study evaluated the knowledge levels of caregivers of pediatric CKD patients and the factors influencing their knowledge. Our data indicate that CKD patients at our clinic are closely and frequently monitored, and disease progression is generally slow. Caregivers of early-stage CKD patients had significantly higher educational levels, whereas caregivers of patients diagnosed at advanced CKD stages or those with a healthcare background demonstrated significantly higher CKD knowledge levels.

Higher CKD knowledge among caregivers was also associated with reduced school absenteeism and better academic performance in their children.

In this study, the mean score of the participants was 64.9 out of 100 and more than half of them had above average scores. In a survey conducted by Gheewala et al., which assessed the level of public knowledge, participants scored 10.3 out of 22 points, with 50% scoring less than 11. Therefore, the level of public knowledge in that study was considered low [13]. Similarly, in a questionnaire study conducted by Okoro et al. with 220 adult CKD patients, those who correctly answered more than 50% of the 28 questions were considered to have a good level of knowledge about CKD, and it was found that 65% of the patients had a low level of knowledge about CKD[9]. Compared with previous studies, the knowledge level of patients' caregivers in our study was higher. When compared across CKD stages, the knowledge scores of caregivers were above 50 in all stages, indicating that their overall level of knowledge was acceptable, regardless of the stage of the disease. On the other hand, while most caregivers reported receiving information about CKD primarily from physicians in our study, nearly half also cited the internet and 17% social media as additional sources. The fact that some participants relied on these channels highlights the importance of developing reliable platforms to ensure accurate dissemination of information to both caregivers and the general public.

The mean CKD stage at the time of diagnosis was stage 3a, whereas the current mean CKD stage was determined as stage 3b in the present study. 63.8% of the current cases were in the early stages of CKD, while 36.2% were in the advanced stages. According to NAPRTCS data, the mean progression time from stage 2–4 CKD to stage 5 CKD has been reported as 4.5 years[4]. Considering that 75% of our patients have been followed in our clinic for more than 5 years and that the mean follow-up duration was 6.5 years, we may suggest that disease progression in our patients was slower compared with the NAPRTCS data. Besides, 45.8% of the patients attended check-ups once a month, and 8.3% more than once a month. In CKD follow-up, monthly visits are mostly recommended for stage 5 patients [13]. In our clinic, although the majority of patients were in the early stages and only 14.9% were in stage 5, nearly half of all patients were scheduled for monthly visits. These findings indicate that CKD patients in our clinic are being monitored more closely. Besides, caregivers reported that 83% of the patients were evaluated by a specialist physician, and nearly half by a faculty member. We consider that the slower progression of the disease compared with other studies may be attributable to our center being a tertiary healthcare institution, the close follow-up involving specialist and faculty physicians, and the frequent monitoring performed.

We observed that higher family income and better educational status of caregivers were associated with higher CKD knowledge levels, although the differences were not statistically significant. Similarly, Loo et al. in Malaysia reported that higher education and socioeconomic status correlated with better knowledge[10]. In our study, knowledge scores tended to increase with advancing CKD stage, except in stage 4. Among caregivers of stage 4 patients, 70% were primary school graduates and 40% had low income, compared with 18.2–28.6% and 22.2–30%, respectively, in other stages. These findings suggest

that the lower knowledge level in stage 4 CKD may be attributed to the predominance of lower educational and socioeconomic backgrounds in this subgroup.

In our study, 17% of the patients had another sibling being followed for CKD. When the CKD knowledge levels of the caregivers were examined, the presence of another sibling with CKD seemed to be associated with a higher level of knowledge. Similarly, in a community-based study conducted by Yabeyu et al., which assessed CKD knowledge in adults, individuals with a family history of CKD had higher knowledge levels[11]. This can be explained by the fact that as the number of family members, particularly those being followed for CKD, increases, families gain greater experience and awareness regarding CKD. On the other hand, different from previous reports in the literature, in our study, caregivers of patients who were healthcare professionals themselves had more above-average CKD knowledge scores compared to those without a healthcare background. This suggests that healthcare professionals within the household or family environment may play an important role in educating and appropriately guiding patient caregivers about the disease.

In this study, caregivers of patients with regular school attendance and higher academic achievement had significantly greater CKD knowledge. Similarly, children of participants with above-average knowledge scores showed lower rates of school absenteeism and higher academic performance. This suggests that better-informed caregivers may more effectively monitor patient issues, support treatment adherence, and seek timely medical attention, potentially preventing hospitalizations. It is well-known that CKD can negatively impact a child's academic performance. Duquette et al. reported that children with CKD had lower intellectual and academic outcomes compared to their peers, with higher rates of special education needs, grade repetition, and school absenteeism. Improved kidney function was associated with better intellectual and academic performance, emphasizing the need for ongoing clinical monitoring and further research[12]. Our findings that higher CKD knowledge among caregivers correlates with better academic outcomes underscore the critical role of family education on the better follow-up of the disease, particularly during childhood when academic achievement is especially important.

We did not detect any relationship was observed between patients' annual eGFR decline or CKD progression over the past two years and either CKD knowledge levels or sociodemographic factors. This likely reflects the effect of frequent outpatient visits and close clinical and laboratory monitoring by the medical staff in our center.

In our study, caregivers of advanced-stage CKD patients had higher CKD knowledge levels than those of early-stage patients, although the difference was not statistically significant. Interestingly, caregivers of early-stage patients had significantly higher educational levels. This may reflect that well-educated and informed individuals are more likely to be aware of CKD itself, ensuring early outpatient hospital admissions, regular medical follow-ups and adherence to treatment, preventing disease progression. Nevertheless, the higher knowledge observed among caregivers of advanced-stage patients despite lower education may result from experiences gained while managing complications during the disease

course. Supporting this, caregivers of patients diagnosed at an advanced stage scored significantly higher not only in total CKD knowledge but also in the categories of ‘CKD symptoms,’ ‘CKD complications,’ and ‘CKD diet’ compared to other caregivers, indicating that much of their knowledge was derived from practical experience with disease-related complications.

When examining specific questions determining CKD knowledge among patient caregivers, we noticed that there were some areas of insufficient knowledge. For example, 21.3% (n = 10) did not know that CKD was a progressive disease and 17% were unaware that medical treatments could slow CKD progression. Besides, while 31.9% correctly knew that herbal treatments do not slow CKD progression, 53.2% were uninformed on this issue and additionally, 14.9% of participants (n = 7) even believed that herbal treatments might slow CKD progression. Similarly, in a community-based study conducted by Gheewala et al. in Australia, 23% of participants believed that herbal treatments could cure CKD, and 49% were unaware that medical treatments could slow disease progression[13]. Although our study population provided more accurate responses compared to that study, the presence of inadequate information or misinformation on CKD in certain areas may be related to some caregivers relying on information sources prone to misinformation, such as social media or television. Therefore, ensuring accurate education by healthcare professionals is considered crucial to prevent potentially harmful practices.

CONCLUSION

In our study, the caregivers had favorable CKD knowledge. However, we detected some domains where they had incorrect or incomplete information. While the physician’s role remains crucial in CKD management, our findings suggest that well-informed caregivers can potentially improve patients quality of life and academic outcomes. We emphasize the importance of assessing patient and caregiver knowledge during outpatient visits, identifying areas of deficiency, providing targeted support, and creating platforms for accurate information dissemination.

The main limitations of our study include the single tertiary center design and the relatively small sample size. Therefore, multicenter studies with increased number of patients are necessary. Nevertheless, up to our knowlege, being the first study to evaluate the knowledge levels of caregivers of pediatric CKD patients, we believe our study will make contribution and provide insight towards CKD management in children.

Declarations

Conflicts of Interest

The authors declare no conflicts of interest.

Ethics Committee Approval

The study was approved by the Ethics Committee of Gazi University Rectorate with decision number 198, dated 13.02.2024.

Consent to Participate

Informed consent was obtained from all individual participants included in the study.

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Data Availability

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

References

1. Sahu G, Kumar S, Acharya S, Talwar D, Annadatha A, Patel M et al (2022) The Act of Prevention: Knowledge, Attitudes, and Perception Among Caretakers of Kidney Disease Patients in Rural Wardha District of Central India. Cureus 14(3):e23058. 10.7759/cureus.23058
2. Soylemezoglu O, Duzova A, Yalçinkaya F, Arinsoy T, Süleymanlar G (2012) Chronic renal disease in children aged 5–18 years: A population-based survey in Turkey, the CREDIT-C study. Nephrol Dialysis Transplantation 27. 10.1093/ndt/gfs366 PubMed PMID: 23115139
3. Harambat J, Madden I, Hogan J (2021) Epidemiology of pediatric chronic kidney disease. Nephrol Ther 17(6):476–484. 10.1016/j.nephro.202106.001 PubMed PMID: 34518130
4. Kamath N, Iyengar A, George N, Luyckx VA (2019) Risk Factors and Rate of Progression of CKD in Children. Kidney Int Rep 4(10):1472–1477. 10.1016/j.ekir.2019.06.004
5. Wong H, Mylrea K, Feber J, Drukker A, Filler G (2006) Prevalence of complications in children with chronic kidney disease according to KDOQI. Kidney Int 70(3):585–590. 10.1038/sj.ki.5001608 PubMed PMID: 16788689
6. Becherucci F, Roperto RM, Materassi M, Romagnani P (2016) Chronic kidney disease in children. Clin Kidney J 9(4):583–591. 10.1093/ckj/sfw047 PubMed PMID: 27478602
7. Mahmoud MA, Ibrahim A, Fadil HA, Alalawi AM, Alnezary FS, Alahmadi Y et al (2023) Assessment of Public Knowledge about Chronic Kidney Disease and Factors Influencing Knowledge Levels: A Cross-Sectional Study. Med (Lithuania) 59(12). 10.3390/medicina59122072 PubMed PMID: 38138176

8. Younes S, Mourad N, Safwan J, Dabbous M, Rahal M, Al Nabulsi M et al (2022) Chronic kidney disease awareness among the general population: tool validation and knowledge assessment in a developing country. BMC Nephrol 23(1). 10.1186/s12882-022-02889-2 PubMed PMID: 35883118
9. Okoro RN, Ummate I, Ohieku JD, Yakubu SI, Adibe MO, Okonta MJ (2020) Kidney Disease Knowledge and Its Determinants Among Patients With Chronic Kidney Disease. J Patient Exp 7(6):1303–1309. 10.1177/2374373520967800
10. Loo LC, Ong KW, Nidzwal AKA, Razali MH, Ahmad N, Naim A et al (2022) Knowledge of chronic kidney disease among undergraduate and postgraduate students in a public university in Klang Valley, Malaysia: A cross sectional study. PLoS ONE 17(9 September). 10.1371/journal.pone.0274038 PubMed PMID: 36149873
11. Yabeyu AB, Haile KT, Belay YB, Tegegn HG (2022) Limited Public Knowledge of Chronic Kidney Disease in a Resource-Limited Setting: A Cross-Sectional Study. Int J Gen Med 15:4997–5003. 10.2147/IJGM.S364632
12. Duquette PJ, Hooper SR, Wetherington CE, Icard PF, Gipson DS (2007) Brief report: Intellectual and academic functioning in pediatric chronic kidney disease. J Pediatr Psychol 32(8):1011–1017. 10.1093/jpepsy/jsm036 PubMed PMID: 17556399
13. Gheewala PA, Peterson GM, Zaidi STR, Jose MD, Castelino RL (2018) Public knowledge of chronic kidney disease evaluated using a validated questionnaire: A cross-sectional study. BMC Public Health 18(1). 10.1186/s12889-018-5301-4 PubMed PMID: 29554891

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