ORIGINAL RESEARCH

Assessing the knowledge of caregivers of children undergoing peritoneal dialysis in Riyadh, Saudi Arabia

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ABSTRACT

Background and objective: Children with end stage renal disease (ESRD) are commonly placed onto chronic peritoneal dialysis (PD) while awaiting a transplant. Those children require a caregiver to assume major responsibility for their treatment. Knowledge of those caregivers is very important to prevent complications. This study aimed to assess the knowledge of caregivers of children undergoing PD in Riyadh.
Methods: A convenient sample of 41 caregivers of children on PD from three hospitals in Riyadh and who met the inclusion criteria participated in this study. Structured questions were developed by the researchers and used to collect data regarding the study that consisted of two parts. The first part included sociodemographic data of children and the caregivers. The second part contained 36 questions that assessed the knowledge of the caregivers.
Results: The majority of caregivers were mothers who were not working. All caregivers were educated, and most were from the central region of Riyadh. It was found that the caregivers had more knowledge than expected, the source of this knowledge was from physicians. There was a high correlation between the knowledge and education level of caregivers. Moreover, there was a significantly statistical correlation between correct answer and sociodemographic data of caregivers' water supply, type of services and distance between home and the nephrology center.
Conclusions and recommendations: Most caregivers have adequate knowledge regarding the care of children with ESRD; however, some weaknesses were identified. The caregivers do not know the symptoms of the disease and they are unable to identify signs of dehydration and the importance of weight to prevent dialysis complications. One third of the sample did not know about the complications of PD. We recommend frequent sessions of PD management and care.

Key Words: Caregivers, Level of knowledge, Peritoneal dialysis, Chronic kidney disease

1. INTRODUCTION

Chronic renal failure (CRF) is a disorder that is becoming more prevalent among all population groups worldwide; it is characterized by a drop in the glomerular filtration rate, causing the loss of the kidney's regulating, excretory and endocrine functions.[1] CRF occurs when the kidney has an issue relating to the concentration of urine, the maintenance of electrolytes, or if there is a protrusion of waste output. In children, renal failure can be severe or inveterate.[2]

For children with chronic kidney disease (CKD), they need medical treatment over their lifetime. This can cause significant discomfort and affect their daily routine and the lifestyle of their families. For children with CKD or peritoneal dialysis (PD), the management process is considered a highly complicated process. Commonly, it requires several medical

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prescriptions, invasive procedures and nutrient supplements provided through the tubes of treatment devices.[3]

Based on dialysis statistics that are provided by the Saudi Center for Organ Transplantation (SCOT), by the end of 2016, 17,687 patients received dialysis, 16,315 were treated by hemodialysis (HD) and 1,372 were treated by PD.[4]

It has been projected that the number of patients with ESRD will increase by approximately 60% in 2020 compared to figures from 2005.[5]

To start PD, children need to be trained on how to perform dialysis at home. Understanding how to carry out dialysis is difficult for adults, but perhaps even more challenging for the parents of children needing it. Most reports agree that PD training programs continue to play an important role in pediatric PD. Several authors' correspondence suggest the need for an organized teaching protocol for the families of children with ESRD.[6]

On the contrary, a dialysis nurse, as a fundamental caregiver, has an essential role in providing constant evaluation, distinguishing the child's complaints about symptoms, providing constant support for medical strategies and providing the care in order to support the families of the children and assist them in exploring their emotions.[7]

The safety of the patient is an essential concern for all healthcare professionals, especially caregivers. They are permanently involved in the patient's care.[8] However, it is important for nurses to develop their knowledge. Eventually, the knowledge of the caregivers is regarded as the heart and soul of every patient. Caregivers' knowledge and skills of practice play a fundamental role in containing and controlling the patients' well-being as this ultimately develops and enhances the quality of care for the patients.

Therefore, caregivers who lack knowledge can cause several issues, such as complications relating to the quality of care for children with PD.[1] This study aims to assess the knowledge of Saudi caregivers of children undergoing PD in Riyadh.

Research questions

In order to fulfil the study aim, the following questions were developed:

(1) What are the sociodemographic characteristics of children with PD and their caregivers?
(2) What is the estimated level of knowledge of the caregivers?
(3) Is there a relationship between sociodemographic characteristics of the children and their caregivers' level of knowledge?

2. STUDY METHODOLOGY

2.1 Setting

Patients were recruited from pediatric nephrology units in three major hospitals in Riyadh, Saudi Arabia that offer free medical services to people.

2.2 Research design

A quantitative descriptive cross-section research approach was adopted in this study.

2.3 Subject

2.3.1 *Sample type*

A sample of 41 caregivers of children on PD participated in this study, all of which met the inclusion criteria.

2.3.2 *Sample size*

A total sample of 41 caregivers out of 107 completed the questionnaire.

2.3.3 *Inclusion criteria*

Saudi caregivers of children undergoing PD.

2.4 Tool of data collection

2.5 Data collection

A structured interview questionnaire was developed after an extensive literature review and consultation with experts in the pediatric field. The questionnaire was modified as per the experts' suggestions. The modified, final version of the questionnaire was used in this study.

2.6 Questionnaire content

The questionnaire included multiple choice questions about the following points:

(1) Sociodemographic data of the children and caregivers.
(2) General information about the children's history of disease and family services provided.
(3) Management of PD, such as diet, catheter care and weight.

2.7 Ethical consideration

- An official letter from the King Saud University (KSU) Nursing College was obtained and submitted to the administration of the participating hospitals for permission to conduct the study.
- Ethical approval was received from the Research Ethics Committee of the Faculty of three hospitals in Riyadh.
- Consent was taken from the caregivers.

2.8 Pilot study

A pilot study for the questionnaire was conducted before data was collected for this study. Data were analyzed using IBM SPSS software package version 20.0. Qualitative data was described using numbers and percentages. Quantitative data was described using means and standard deviations. Significance levels of the obtained results was set at the 5%.

The tests used in this study were:

(1) Chi-squared test: For categorical variables, to compare the different groups.
(2) Monte Carlo correction: Correction of the chi-squared test when more than 20% of the cells had an expected count less than five.

3. RESULTS

3.1 Socio-demographic data of the children

Table 1 summarizes the characteristics of the pediatric PD patients, including age, gender, child birth order, educational level and age of disease diagnosis. Regarding age, this was grouped into five age categories: less than one-year old, between one and three-year old, between four and seven-year old, between eight and 12-year old and between 13 and 18-year old. Most of the children were aged between 8 and 12-year (31.7%), 9.8% were less than one year, 22.0% were between one and three years, 22.0% were four to seven-years old and 14.6% were eight to 18-year old. Regarding gender, 75.6% of the sample were male and 24.4% were female.

Concerning child birth order, about half of the children were the first born (46.3%), 24.4% were second, 17.1% were third, 9.8% were fourth and 2.4% were in the “other” category.

Regarding educational level, about half of the study’s sample had no schooling (48.8%), 39.0% were primary-level educated, 7.3% were preparatory and 4.9% were secondary. The age of disease diagnosis was the fifth variable, and this was categorised into four groups: 48.8% were less than one-year old, 31.7% were one to three years, 7.3% were four to six years and 12.2% were older than six years.

Table 1. Socio-demographic data of the children

Variable	Categories	Frequency	Percentage (%)
Child Age	Less than 1 year	4	9.8
	1 to 3 years	9	22.0
	4 to 7 years	9	22.0
	8 to 12 years	13	31.7
	13 to 18 years	6	14.6
Gender	Male	31	75.6
	Female	10	24.4
Child birth order	First	19	46.3
	Second	10	24.4
	Third	7	17.1
	Fourth	4	9.8
	Other	1	2.4
Educational level	Primary	16	39.0
	Preparatory	3	7.3
	Secondary	2	4.9
	No schooling	20	48.8
Age of disease diagnosis	Less than 1 year	20	48.8
	1 to 3 years	13	31.7
	4 to 6 years	3	7.3
	Older than 6 years	5	12.2

3.2 Demographic data of caregivers

Table 2 summarizes the caregivers’ characteristics including age, gender, relation to the child, educational level, marital status, family type, family size, type of job, household income, family history regarding the disease, geography-region, housing type and internal water supply. One third of caregivers’ ages ranged between 25 and 34 years (36.6%), 22.0% were aged between 18 and 24 years, 29.3% were aged between 35 and 44 years, and 12.2% were older than 45 years. Regarding gender, 12.2% of the caregivers were male, and 87.8% were female. Regarding the caregivers’ relation to the child, 85.4% were their mother, 7.3% were their father, 2.4% were their child and 4.9% were their assistant. Regarding their educational level, 22.0% of the caregivers were in the category "read and write", 4.9% had completed primary school, 22.0% had completed secondary school, 34.1% were high-school graduates and 17.1% had a bachelor's degree. Most of the care givers were married (85.4%), while 9.8% were separated and 4.9% were divorced. Regarding family type, 56.1% classified themselves in the "nuclear family" category, 39.0% in the "extended family", 2.4% in the "extended family", 2.4% in the "step-family" and 2.4% in the "grandparent" category. Regarding family size, 48.8% had a "small family" (parent/s and less than five children), 43.9% had a "big family" (parent/s and more than five children) and 7.3% in the "parent/s, children and one relative", i.e. grandmother, grandfather, uncle or aunty. In respect of employment, more than three quarters of the caregivers were "not working" (80.5%), while 2.4% worked "office hours", 12.2% had "shift hours (eight hours)" and 4.9% had "shifting hours (12 hours)". Three quarters of the household incomes ranged between "3,000 to 8,000 SR" (73.2%), while 9.8% had "less than 3,000 SR" and 17.1% earned between "9,000 to 14,000 SR". In relation to family history of the disease, 24.4% of the participants classified themselves as "first degree", 7.3% were "second degree" and 68.3% had "no history". Around half of the caregivers' geography-region was the "central region" (48.8%), while 9.8% were from the "northern region", 19.5% from the "eastern region", 17.1% from the "western region" and 4.9% from the "southern region". Regarding housing type, 78.0% of the participants live in an "apartment", 17.1% live in a "villa" and 4.9% selected "other type". Concerning internal water supply, 87.8% of participants have a "piping system" and 12.2% have "no piping system".

3.3 General information about PD issues

Table 3 illustrates the caregivers' responses to general information about PD issues. 95.1% of participants selected "government hospital" as the type of facility their child seeks treatment at, 2.4% selected "private hospital" and 2.4% selected "Saudi Society of Nephrology". Regarding distance from the nephrology center, 2.4% of participants lived "less than 5 km", 12.2% lived between "5 and 10 km", 24.4% lived between "5 and 15 km" and 61.0% lived "more than 15 km" away. More than half of the participants relay the selection of the option of the dialysis to doctor (58.5%), while 7.3% from Select the option of the dialysis are "Mother", and 34.1% are "Child condition". Concerning the caregivers' support to the child, 43.9% from supports the child are "self-expression", 36.6% are "alleviating feeling" and 19.5% are "strength self-image". About three quarters of the children perform PD on a daily basis (73.2%), while 7.3% perform it "twice weekly" and 19.5% selected "according to the child's case". Regarding the CRF source of information, 22.0% of participants selected "doctor", 14.6% chose the "nurse" option, 14.6% selected "health educator", 2.4% chose "friend" and 46.3% selected "other sources". Approximately three quarters of caregivers responded that their child has been admitted to hospital due to complications (73.2%) and 26.8% selected "no complications" had been encountered. Concerning the list of associated health problems, 9.8% identified "dental problems", 31.7% stated "high-blood pressure", 9.8% chose "anemia", 41.5% selected "more than one problem" and 7.3% chose the "no problems" category.

Table 4 shows the difference between caregivers' understanding of the definition the disease; more than three quarters of the sample responded correctly (82.9%), while 17.1% of the participants' responses were incorrect. Regarding the differences between acute and chronic diseases, 70.7% of the sample were aware, 17.1% were not and 12.2% did not know. Half of the sample thought that the main reason for CRF was diabetes (48.8%), while 24.4% believed it to be high-blood pressure and 26.8% thought it was caused by infection. Regarding the effects of the disease on growth and development, a majority of the sample were aware of this (73.2%), 14.6% were not and 12.2% were not sure. Regarding the long-term prognosis, 78.0% of the sample were aware, 12.2% were not and 9.8% were unsure. One third of the sample (39.0%) believed that "urinating more or less than normal" was the most significant symptom of the disease, while 7.3% of participants thought "feeling tired", 19.5% thought "nausea and vomiting", 7.3% thought "back pain", 12.2% believed "headaches", 7.3% thought "cyanosis" and 7.3% thought "coughing" were the reasons. Regarding monitoring the child's bodily fluids, 97.6% of the sample were aware this is important; however, 2.4% of participants did not know. The mean of dehydration for about one third of the sample (34.1%) was "loss of weight", while 29.3% thought "tiredness or weakness", 31.7% thought "decreased urinary output", 2.4% thought "other reasons" and "do not know". Regarding the mean of fluid over weight, the participants responded as follows: 26.8% "increased weight", 73% "increased urinary output", 34.1% "swelling of ankles or fingers", 24.4% "puffiness around the eyes" and 7.3% "do not know". Two thirds of the sample (65.9%) were aware that a consistent weight before and after dialysis is important; however, 24.1% were not aware. Concerning exercise, 36.6% of the sample agreed that children on PD must limit participating in sporting activities, but 63.4% did not agree or know this was important. For clinical visits, more than three quarters (80.5%) of the sample agreed that it is important to bring the child's daily dialysis records, whereas 19.5% of participants did not know.

Table 2. Demographic data of caregivers

Variable	Categories	Frequency	Percentage (%)
Age	18 to 24 years	9	22.0
	25 to 34 years	15	36.6
	35 to 44 years	12	29.3
	More than 45 years	5	12.2
Gender	Male	5	12.2
	Female	36	87.8
Relation to child	Mother	35	85.4
	Father	3	7.3
	Child	1	2.4
	Relative	0	0.0
	Assistant	2	4.9
Education level	Illiterate	0	0.0
	Read and write	9	22.0
	Completed primary school	2	4.9
	Completed secondary school	9	22.0
	High school graduate	14	34.1
	Bachelor’s degree	7	17.1
	Other advanced degree beyond a Bachelor’s degree	0	0.0
Marital status	Married	35	85.4
	Separated	4	9.8
	Divorced	2	4.9
	Nuclear Family	23	56.1
	Extended Family	16	39.0
	Stepfamily	1	2.4
	Grandparent Family	1	2.4
Family size	Small (parent and children less than 5)	20	48.8
	Big (parent and children more than 5)	18	43.9
	Parent, children and one of the relatives: grandmother, grandfather, uncle and aunty.	3	7.3
Type of job	Not working	33	80.5
	Office hours	1	2.4
	Shift of 8 hours	5	12.2
	Shift of 12 hours	2	4.9
Household income	Less than 3,000 SR	4	9.8
	3,000 to 8,000 SR	30	73.2
	9,000 to 14,000SR	7	17.1
	15,000 to 20,000 SR	0	0.0
Family history of the disease	There is no history	28	68.3
	There is history from first degree	10	24.4
	There is history from second degree	3	7.3
Geography – region	Central region	20	48.8
	Northern region	4	9.8
	Eastern region	8	19.5
	Western region	7	17.1
	Southern region	2	4.9
Housing type	Apartment	32	78.0
	Villa	7	17.1
	Other	2	4.9
Internal water supply	Piping system	36	87.8
	No piping system	5	12.2

Table 5 illustrates that 87.8% of children require a restricted diet, but 12.2% do not or are unaware if they do. 80.5% from the fluid intake should not be excessive, but 19.5% “may be Excessive”. 82.9% of children know that the types of food listed should be limited (bananas, oranges, cantaloupes, nectarines, baked potatoes, spinach, squash and tomato sauce) because they are rich in potassium, but 17.1% did not know. 85.4% of children knew they should eat enough protein, such as meat, poultry, fish, tofu and low sodium cottage cheese, but 14.6% did not know. 70.7% of children know that phosphorus intake needs to be restricted, such as milk and dairy products, dried beans, peas, lentils, animal organs, whole wheat and processed foods containing additives, but 29.3% were unaware. 85.4% of children knew it was important to have low levels of salt in their diet, whereas 14.6% did not know. 75.6% of children agreed that it is important to avoid fast foods and packaged or processed foods because they contain significant amounts of salt, but 24.4% did not know. 70.7% of children knew to minimize their sugar intake by eating fewer sweets and starchy food, such as baked goods, corn and potatoes, as well as keep active; however, 29.3% did not know this. In general, 79.9% of the sample were aware of their dietary requirements, but 20.1% did not know.

Table 3. General information about PD issues

Variable	Categories	Frequency	Percentage (%)
Type of facility your child visits	Government hospital	39	95.1
	Private hospital	1	2.4
	Saudi Society of nephrology	1	2.4
Distance from nephrology center	Less than 5 km	1	2.4
	5 to 10 km	5	12.2
	5 to 15 km	10	24.4
	More than 15 km	25	61.0
Who selects the option of dialysis?	Father	0	0.0
	Mother	3	7.3
	Child condition	14	34.1
	Doctor	24	58.5
How does the caregiver support the child?	Self-expression	18	43.9
	Alleviating feeling	15	36.6
	Strength self-image	8	19.5
How often does a child perform PD?	Daily	30	73.2
	Twice weekly	3	7.3
	According to the child's case	8	19.5
The source of information regarding CRF	Doctor	9	22.0
	Nurse	6	14.6
	Health educator	6	14.6
	TV	0	0.0
	Friend	1	2.4
	Education materials	0	0.0
	Other	19	46.3
Has your child been admitted to hospital due to any complications?	Yes	30	73.2
	No	11	26.8
Does your child have any of the following problems?	Dental problems	4	9.8
	High blood pressure	13	31.7
	Anemia	4	9.8
	More than one problem	17	41.5
	No	3	7.3

In addition, Table 5 illustrates that 97.5% of participants always handle their children's catheter with clean hands; however, 2.4% do not. 92.7% of the sample keep their children's exit site clean and dry, and 7.3% do not. 85.4% of participants inspect the catheter site for redness, swelling and pain, as well as cracks or holes in the catheter, whereas 14.7% do not. 75.6% of the sample inspect the catheter site for drainage on the dressing, and 24.2% do not. In general, 87.8% of the sample are aware of catheter care information; however, 12.2% do not.

Table 4. Knowledge of caregivers regarding (disease and, monitoring the child's body fluids, exercise, and clinical visits)

Variable	Categories	Frequency	Percentage (%)
What is the definition of your child's disease?	Correct	34	82.9
	Incorrect	7	17.1
Do you know the difference between acute and chronic diseases?	Yes	29	70.7
	No	7	17.1
	I do not know	5	12.2
What do you think the main causes of CRF?	High blood pressure	10	24.4
	Diabetes	20	48.8
	Infection	11	26.8
	Birth defect	0	0.0
	Trauma	0	0.0
	Other	0	0.0
	I do not know	0	0.0
Do you know the effects of the disease on growth and development?	Yes	30	73.2
	No	6	14.6
	I do not know	5	12.2
Do you know that it has a long-term prognosis?	Yes	32	78.0
	No	5	12.2
	I Do not know	4	9.8
The symptoms of the disease	Urinating more than normal or less than normal	16	39.0
	Feeling tired	3	7.3
	Nausea and vomiting	8	19.5
	Back pain	3	7.3
	Headache	5	12.2
	Cyanosis	3	7.3
	Cough	3	7.3
Monitoring your child's bodily fluids			
Do you know it is important to keep monitoring your child's bodily fluids?	Yes	40	97.6
	No	0	0.0
	I Do not know	1	2.4
What is the meaning of dehydration?	Loss of weight	14	34.1
	tiredness or weakness	12	29.3
	decreased urinary out put	13	31.7
	Other	1	2.4
	I do not know	1	2.4
What is the meaning of fluid over weight?	Increased weight	11	26.8
	increased urinary output	3	7.3
	Swelling of ankles or fingers	14	34.1
	puffiness around the eyes	10	24.4
	Other	0	0.0
	I do not know	3	7.3
Do you know that a consistent of weight of your child is important before and after dialysis?	Yes	27	65.9
	No	3	7.3
	I do not know	11	26.8
Does your child on PD require restricted sports?	Yes	15	36.6
	No	16	39.0
	I do not know	10	24.4
Clinic Visit	Yes	33	80.5
	No	1	2.4
	I do not know	7	17.1

Table 5. Knowledge of caregivers regarding (diet, catheter care, weight, medications and common complications of PD)

Field	No.	Items	Yes		No		I do not know		Rank
			F	%	F	%	F	%	
Diet	1	Does your child (patient) require a restricted diet?	36	87.8	4	9.8	1	2.4	1
	4	Do you know that your child should eat enough protein from meat, poultry, fish, tofu, and low sodium cottage cheese?	35	85.4	1	2.4	5	12.2	2
	6	Do you know that it is important to limited levels of salt in your child’s diet?	35	85.4	0	0.0	6	14.6	2
	3	Do you know that the following types of food below should be limited because it is rich in potassium? (banana, oranges, cantaloupes and nectarines, baked potatoes, spinach, squash and tomato sauce)	34	82.9	0	0.0	7	17.1	3
	2	Should fluid intake not be excessive?	33	80.5	6	14.6	2	4.9	4
	7	Is it important to avoid most fast foods, packaged, and processed foods because they contain significant amounts of salt?	31	75.6	0	0.0	10	24.4	5
	5	Do you know that phosphorus needs to be restricted, such as milk and milk dairy products, dried beans, peas, lentils, animal organs, whole wheat and processed foods containing phosphorus additives?	29	70.7	4	9.8	8	19.5	6
	8	Do you know that you can minimize the sugar intake in your child’s diet and keep them active by eating fewer sweets and starchy food, such as baked goods, rice, corn or potatoes?	29	70.7	2	4.9	10	24.4	6
		Total	262	79.9	17	5.2	49	14.9	
Catheter care	1	Always handle your child’s catheter with clean hand.	40	97.6	0	0.0	1	2.4	1
	2	Keep your child exit site clean and dry.	38	92.7	0	0.0	3	7.3	2
	4	Inspect catheter site for redness, swelling or pain crackles or tiny holes in the catheter	35	85.4	4	9.8	2	4.9	3
	3	Inspect catheter site for drainage on dressing	31	75.6	4	9.8	6	14.6	4
		Total	144	87.8	8	4.9	12	7.3	
Weight	1	Is it very important to weigh your child at the same day every day?	23	56.1	8	19.5	10	24.4	1
	4	Is it important to place the scales on a smooth, flat surface?	22	53.7	4	9.8	15	36.5	2
	3	Is it important to use the same scales to measure your child’s weight?	21	51.2	8	19.5	12	29.3	3
	2	Is it important to weigh your child wearing the same amount of clothing?	17	41.5	11	26.8	13	31.7	4
		Total	83	50.6	31	18.9	50	30.5	
Medications	1	Is it very important to take your child (patient) medications as prescribed?	36	87.8	2	4.9	3	7.3	1
	2	Is it important to inform the health team if there are any unexpected side effects from taking the medication?	36	87.8	0	0.0	5	12.2	1
		Total	72	87.8	2	2.4	8	9.8	
Common Complications of PD	4	Had you notice any pinkish or bloody effluent?	38	92.7	1	2.4	2	4.9	1
	6	Pain during any part of your dialysis exchange, it is important to let your dialysis team know?	36	87.8	2	4.9	3	7.3	2
	7	If the child develops any of complications, should the health care center be informed?	36	87.8	2	4.9	3	7.3	2
	3	The nurse/doctor advises you as a caregiver when and how to add Heparin into your dialysate if there is any blockage?	35	85.4	1	2.4	5	12.2	3
	1	The most common complication infections on PD are peritonitis and exit site infection?	34	82.9	2	4.9	5	12.2	4
	5	Is a hernia a weak spot in the muscle of the abdomen or groin that is evident as a bulge or a bump, considered as a complication of PD?	28	68.3	0	0.0	13	31.7	5
	2	Effluent fibrins, white stringy fibers can blocks the catheter and block the flow of dialysate?	26	63.4	2	4.9	13	31.7	6
		Total	233	81.2	10	3.5	44	15.3	

Table 5 also illustrates that 56.1% of the sample agree that it is important to weigh their child at the same time, every day; however, 43.9% do not know. 53.7% of the sample agree that it is important to place the scales on a smooth, flat surface, and 46.3% do not know. 51.2% of the sample agree that it is important to use the same scales to weigh their child, and 48.8% do not know. 41.5% of the sample agree that it is important to weigh your child when they are wearing the same amount of the clothing, whereas 58.5% do not know. In general, 50.6% of the sample know the advantages of weighing their child, but 49.4% do not know about Catheter care.

Table 5 illustrates that 87.8% of the sample agree that it is important for their child (patient) to take their medication as prescribed, whilst 12.1% do not know. 87.8% of the sample agree that it is it important to inform the health team if there are any unexpected side effects from the medication, and 12.2% do not know. In general, 87.8% of the sample know information about their child's medication, but 12.2% do not know.

Table 5 shows that 92.7% of the sample notice pinkish or bloody effluent from their child, and 7.3% do not notice. 87.8% of the sample agree that if pain is experienced during any part of the dialysis exchange, it is important to inform the dialysis team; however, 12.2% do not know. 87.8% of the sample agree that if their child develops complications, the health team should be informed; however, 12.2% did not know. 85.4% of the sample agree that when and how caregiver need to add Heparin into the dialysate if there is any blockages as advised by nurse or doctor the nurse/doctor advised, and 14.6% do not know. 82.9% of the sample agree that the most common complications or infections related to PD are peritonitis and exit site infection, and 17.1% do not know. 68.3% of the sample agree that a hernia; a weak spot in the muscle of the abdomen or groin as represented by a bulge or bump, is considered as a complication of PD, and 31.7% do not know. 63.4% of the sample agree that effluent fibrins or white stringy fibers can block the catheter and flow of dialysate, and 36.6% do not know. In general, 81.2% of the sample know about common complications of PD, but 18.8% do not know any information about medications.

There is a significant correlation between the correct answers provided by the caregivers and their sociodemographic status. We used a chi-squared test to test the correlation between the correct answers and sociodemographic data of caregivers, and the results are presented in Table 6. It shows a significant correlation between the correct answers and the housing type and internal water supply variables since the *p*-value is equal to .006 and .006, respectively, and this is < .05. There is no relation between the correct answers and the remaining variables as the *p*-value > .05.

Table 6. Correlation between the correct answers and sociodemographic data of caregivers

Socio-Demographic Data of Child	Chi-square test	*p*-value
Caregiver age	0.507	.086
Gender	0.034	.853
Relation to child	1.178	.758
Education level	8.263	.082
Marital status	0.589	.745
Family type	6.913	.075
Family size	1.133	.567
Type of job	0.677	.877
Household income	1.800	.407
Family history of the disease	5.130	.077
Geography-region	3.011	.556
Housing type	10.225	.006
Internal water supply	7.411	.006

Table 7 indicates that most of the caregivers have excellent information (78.0%) and 10% to 12% ranged from good to very good respectively.

Table 7. Distribution of the studied cases according to overall knowledge of caregivers (n = 41)

Overall knowledge	No.	%
Poor: 0-12	0	0.0
Good: 13-25	4	9.8
Very good: 26-38	5	12.2
Excellent: 39-49	32	78.0
Total score		
Min.-Max.	21.0-49.0	
Mean ± SD.	41.05 ± 7.94	

Table 8 shows that the only significant relationship was the education level of caregivers when using a chi-squared test (11.089, *p*-value = .047).

Table 9 demonstrates that there was no significant relationship between the caregivers' overall knowledge and sociodemographic data. Table 10 illustrates that the only significant correlation of the caregivers' overall knowledge and sociodemographic data was evident in the internal water supply variable (*p*-value = .009). Table 11 shows that a significant relationship between the caregivers' overall knowledge and general information about PD issues was evident in the type of facility offered by different agencies (*p*-value = .004), and the distance between the nephrology center and home (*p*-value < .001).

Table 8. Relationship between overall knowledge of caregivers according to the sociodemographic data of child (n = 41)

	Overall knowledge						χ^2	^{MC}p
	Good: 13-25 (n = 4)		**Very good: 26-38 (n = 5)**		**Excellent: 39-49 (n = 32)**			
	No.	**%**	**No.**	**%**	**No.**	**%**		
Child age								
Less than 1 year	1	25.0	0	0.0	3	9.4	4.967	.826
1 to 3 years	1	25.0	1	20.0	7	21.9		
4 to 7 years	0	0.0	1	20.0	8	25.0		
8 to 12 years	1	25.0	3	60.0	9	28.1		
13 to 18 years	1	25.0	0	0.0	5	15.6		
Gender								
Male	4	100.0	4	80.0	23	71.9	1.115	.812
Female	0	0.0	1	20.0	9	28.1		
Child birth order								
First	0	0.0	1	20.0	18	56.3	12.176	.069
Second	1	25.0	2	40.0	7	21.9		
Third	2	50.0	2	40.0	3	9.4		
Fourth	1	25.0	0	0.0	3	9.4		
Other	0	0.0	0	0.0	1	3.1		
Educational level								
Primary	1	25.0	3	60.0	12	37.5	11.089*	.047*
Preparatory	2	50.0	0	0.0	1	3.1		
Secondary	0	0.0	1	20.0	1	3.1		
No schooling	1	25.0	1	20.0	18	56.3		
The age of disease diagnosis								
Less than 1 year	3	75.0	3	60.0	14	43.8	2.481	.913
1 to 3 years	1	25.0	1	20.0	11	34.4		
4 to 6 years	0	0.0	0	0.0	3	9.4		
More than 6 years	0	0.0	1	20.0	4	12.5		

Note. χ^2, p: χ^2 and p-values for the chi squared test; ^{MC}p: p value for Monte Carlo for the chi squared test; $*p \leq .05$.

4. DISCUSSION

ESRD, as a chronic illness in children, is a serious, ongoing, physical health condition that has a range of relatively mild to severe or life-threatening disorders that continually or repeatedly disrupt normal development in relation to physical, emotional, psychological, social, economic and spiritual aspects. By nature, children are dependent physically, mentally and developmentally, so their family members play a great role and have a big responsibility for taking care of them, therefore, it is important to assess their knowledge.[3]

The findings from this study reflects that sociodemographic characteristics of the child age range from 8-12 was 32%, 87% male child nearly 50% do not register to school system and their age when the disease diagnosis less than one year (during infancy). The same result was supported by El-Karmalawy et al. (2015) and Parham (2011).[3,9] However, El Sayed's (2012) results contradict these findings.[10] The results of this study indicated that the majority of children were males; this is supported by the study of Samra et al. (2009).[11] However, this result is in contrast to El-Karmalawy et al.'s (2015) study; the majority of children were females.[3] The children's education approved by results which showed that 39% of the children were at primary level; this is supported by Wong et al. (2014).[12]

The results of this study indicate that more than half of the caregivers' age ranges between 30 and 40; this result is supported by El-Karmalawy et al. (2015) and Parham (2011).[3,9] Mothers as responsible for the care of child it is observed in this study and other studies. This is likely due to the fact the females and mothers are naturally the caregivers in a family, unlike males. However, El-Karmalawy et al. (2015) illustrated that more than half of the caregivers were illiterate, unlike this current study that indicated that all caregivers could at least can read and write.[3] Moreover, the study of Batista et al. (2016) showed that more than half of the caregivers of children and adolescents undergoing hemodialysis or PD did not finish elementary school, and the previous results showed that most of the caregivers were married; this is supported by El- Karmalawy et al. (2015).[1,3]

Table 9. Relationship between the caregivers' overall knowledge and their sociodemographic data (n = 41)

	Overall knowledge						χ^2	^{MC}p
	Good: 13-25 (n = 4)		**Very good: 26-38 (n = 5)**		**Excellent: 39-49 (n = 32)**			
	No.	**%**	**No.**	**%**	**No.**	**%**		
Caregiver age								
18 to 24 years	1	25.0	1	20.0	7	21.9	2.476	.960
25 to 34 years	1	25.0	2	40.0	12	37.5		
35 to 44 years	2	50.0	2	40.0	8	25.0		
More than 45 years	0	0.0	0	0.0	5	15.6		
Gender								
Male	1	25.0	1	20.0	3	9.4	2.089	.302
Female	3	75.0	4	80.0	29	90.6		
Relation to child								
Mother	3	75.0	4	80.0	28	87.5	8.014	.245
Feather	1	25.0	0	0.0	2	6.3		
Child	0	0.0	1	20.0	0	0.0		
Assistant	0	0.0	0	0.0	2	6.3		
Education level								
Read and write	2	50.0	2	40.0	5	15.6	5.316	.787
Completed primary school	0	0.0	0	0.0	2	6.3		
Completed secondary school	1	25.0	1	20.0	7	21.9		
High school graduate	1	25.0	2	40.0	11	34.4		
Bachelor's degree	0	0.0	0	0.0	7	21.9		
Marital status								
Married	3	75.0	4	80.0	28	87.5	4.474	.333
Separated	1	25.0	0	0.0	3	9.4		
Divorced	0	0.0	1	20.0	1	3.1		
Family type								
Nuclear Family	2	50.0	2	40.0	19	59.4	8.096	.308
Extended Family	1	25.0	3	60.0	12	37.5		
Stepfamily	1	25.0	0	0.0	0	0.0		
Grandparent Family	0	0.0	0	0.0	1	3.1		
Family size								
Small (parent and children less than 5)	1	25.0	1	20.0	18	56.3	6.306	.155
Big (parent and children more than 5)	2	50.0	3	60.0	13	40.6		
Parent, children and one of the relative grandmother, grandfather, uncle and aunty.	1	25.0	1	20.0	1	3.1		

Note. χ^2, p: χ^2 and p values for the chi squared test; ^{MC}p: p value for Monte Carlo for the chi squared test; $*p \leq .05$.

Table 10. Relationship between the caregivers' overall knowledge and sociodemographic data (n = 41) "continue"

	Overall knowledge						χ^2	^{MC}p
	Good: 13-25 (n = 4)		**Very good: 26-38 (n = 5)**		**Excellent: 39-49 (n = 32)**			
	No.	**%**	**No.**	**%**	**No.**	**%**		
Type of job								
Not working	3	75.0	5	100.0	25	78.1	3.699	.776
Office hours	0	0.0	0	0.0	1	3.1		
Shifting 8 hours	1	25.0	0	0.0	4	12.5		
Other	0	0.0	0	0.0	2	6.3		
Household income								
Less than 3,000 SR	0	0.0	0	0.0	4	12.5	1.350	1.000
3,000 to 8,000 SR	3	75.0	4	80.0	23	71.9		
9,000 to 14,000 SR	1	25.0	1	20.0	5	15.6		
Family history with the disease								
There is no history	3	75.0	3	60.0	22	68.8	2.122	.809
There is history from first degree	1	25.0	1	20.0	8	25.0		
There is history from second degree	0	0.0	1	20.0	2	6.3		
Geography-region								
Central region	1	25.0	3	60.0	16	50.0	9.051	.217
Northern region	1	25.0	0	0.0	3	9.4		
Eastern region	0	0.0	0	0.0	8	25.0		
Western region	2	50.0	2	40.0	3	9.4		
Southern region	0	0.0	0	0.0	2	6.3		
Housing type								
Apartment	2	50.0	4	80.0	26	81.3	4.534	.227
Villa	1	25.0	1	20.0	5	15.6		
Other	1	25.0	0	0.0	1	3.1		
Internal water supply								
Piping system	1	25.0	5	100.0	30	93.8	9.913*	.009*
No piping system	3	75.0	0	0.0	2	6.3		

Note. χ^2, p: χ^2 and p values for the chi squared test; ^{MC}p: p value for Monte Carlo for the chi squared test; $*p \leq .05$.

Generally, the results of this study show that most of the children come from a nuclear family, the mother is a housewife and the joint income ranges between 800 and 2,000$; this is similar to the El- Karmalawy et al. (2015) study.[3] Bhatti et al. (2012) contradicted this result as he found that 65% of children were living in extended families.[13] His findings also showed that 68% of children had no family history of the disease; this is supported by El-Karmalawy et al. (2015).[3] Thus, this study indicated that the majority of caregivers live in an apartment; however, this contradicts the Batista et al. (2016) study that indicated 90% of children and adolescents undergoing hemodialysis or PD lived in a villa and 10% lived in an apartment. Furthermore, the results also indicate that most of the household had a piping system in villas; this finding is supported by Batista et al. (2016).[1]

The results of this study showed that 95% of the children visit government hospitals to undergo hemodialysis; the philosophy of the Saudi Government is every citizen has the right to access healthcare.

The results showed that more than 61% of the caregivers and children have to travel more than 15 km in order to get to their nephrology center; this finding contradicts Morton et al. (2011) who stated that patients and caregivers have to travel only 10 km.[14] Therefore, a close proximity to chronic dialysis services would ease the travel burden on patients with ESRD and researchers recommended that the MOH increase the number of PD centers to decrease risk of complications of this type of this treatment.

Table 11. Relationship between the overall knowledge and general information about PD issues (n = 41)

	Overall knowledge						χ^2	^{MC}p
	Good: 13-25 (n = 4)		**Very good: 26-38 (n = 5)**		**Excellent: 39-49 (n = 32)**			
	No.	**%**	**No.**	**%**	**No.**	**%**		
Type of facility your child visits								
Government hospital	3	75.0	4	80.0	32	100.0	10.920*	.044*
Private hospital	1	25.0	0	0.0	0	0.0		
Saudi Society of Nephrology	0	0.0	1	20.0	0	0.0		
Distance from nephrology center								
Less than 5 km	0	0.0	0	0.0	1	3.1	22.382*	< .001*
5 to 10 km	3	75.0	2	40.0	0	0.0		
5 to 15 km	1	25.0	2	40.0	7	21.9		
More than 15 km	0	0.0	1	20.0	24	75.0		
Who selects the option of dialysis?								
Mother	0	0.0	0	0.0	3	9.4	1.596	.881
Child	1	25.0	1	20.0	12	37.5		
Doctor	3	75.0	4	80.0	17	53.1		
How does the caregiver support the child?								
Self-expression	2	50.0	4	80.0	12	37.5	3.173	.524
Alleviating feeling	1	25.0	1	20.0	13	40.6		
Strength self-image	1	25.0	0	0.0	7	21.9		
The source of information used for CRF								
Doctor	2	50.0	2	40.0	26	81.3	7.445	.064
Nurse	1	25.0	1	20.0	1	3.1		
Health educator	1	25.0	2	40.0	5	15.6		
Has your child been admitted due to any complications?								
Yes	1	25.0	1	20.0	7	21.9	1.139	1.000
No	3	75.0	3	60.0	20	62.5		
If yes, how many times?	0	0.0	1	20.0	5	15.6		
Does your child have any of the following problems?								
Dental problems	2	50.0	2	40.0	26	81.3	4.957	.061
High blood pressure	2	50.0	3	60.0	6	18.8		
The symptoms of the disease	(n = 1)		(n = 1)		(n = 15)			
Urinating more or less than normal	0	0.0	0	0.0	2	13.3	7.618	1.000
Feeling tired	1	100.0	1	100.0	5	33.3		
Nausea and vomiting	0	0.0	0	0.0	1	6.7		
Back pain	0	0.0	0	0.0	3	20.0		
Headache	0	0.0	0	0.0	4	26.7		

Note. χ^2, p: χ^2 and p values for the chi squared test; ^{MC}p: p value for Monte Carlo for the chi squared test; *$p \leq .05$.

The findings revealed that 43% of caregivers support their child by self-expression and 36% do so by alleviating feelings; this result is supported by Low et al. (2009) and Mashayekhi et al. (2015).[15, 16]

Regarding catheter care, most of the participants have good knowledge about it (87%); this result is consistent with the study by Batista et al. (2016).[1] Although, the caregiver's knowledge on nutrition, medication and complications relating to PD is high; approximately 17%-30% of the participants have poor/inadequate knowledge about fluid intake and food restrictions, such as sugar, milk, dairy products, beans, peas, salt, packaged and processed food, as well as medication and the associated complications of PD. The same results were found by Kamal (2007) and Banchit (2003).[17, 18]

Doctors and nurses represent only 37% of the source of ESRD information; this is serious as they provide the most amount of information to small communities and should be given more time to provide clarification, repetition and reinforcement of information.

5. CONCLUSION

Based on the results of this study, it was found that the majority of caregivers were females, mothers of the children and not working. All of the caregivers were educated and most of them were from the central region of Riyadh. It was also found that their overall level of knowledge was excellent.

Recommendation

(1) Continuous educational programs for all patients receiving hemodialysis and their families to improve their knowledge about treatment and self-care.
(2) Provision of self-care booklets to patients undergoing hemodialysis should be available in all hemodialysis units and given to all newly admitted patients.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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