Mothers Caring for Children Suffering from Chronic Kidney Disease

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Abstract

Background: Chronic kidney disease (CKD) is known to be a major public health concern worldwide with increasing prevalence and incidence that threatens to reach a true epidemic. Its actual prevalence and incidence may be underestimated by epidemiologic data as it is usually asymptomatic, especially in early stages. ***The study aimed* to** assess mothers' care for their children suffering from chronic kidney disease. ***Research design:*** Descriptive analytical design. ***Setting:*** The study was conducted at Pediatric Specialist Clinics nephrology clinic at Pediatric hospital affiliated to Ain Shams University hospitals. ***Sample:*** A purposive sample was used for choosing the study subjects; composed of 75 mothers of children diagnosed with Chronic Kidney Disease. ***Tools:*** an interviewing questionnaire for assessing the socio-demographic characteristics of the studied children and their mothers, mother's knowledge and reported practices about the care of their children with Chronic Kidney Disease. ***Results:*** Study finding that, the mean age of studied children with chronic kidney disease was 7.51±1.13, regarding **sex** 57.3% of them were males, the mean age of studied mothers is 35.20±5.28 years old, whenever 22.7% have university education And 42.7% of them were housewife.. ***Conclusion:*** The result of study concluded that, there was no significant correlation between the total mothers' knowledge about chronic kidney diseases among studied children and reported practices regarding the care of children suffering from chronic kidney diseases.. ***Recommendations:***: Periodic counseling program to all mothers had children suffering from Chronic Kidney Disease who attended to outpatient clinics about diseases treatment, prevention and control measures.

Keywords: Children with Chronic Kidney Disease, mothers' care

Introduction

CKD is a growing public health problem worldwide with increasing incidence and prevalence. The prevalence of CKD in children is much lower than that in adults, ranging from 15 to 75 cases per 1 million children. CKD in children is associated with serious consequences, including increased risk of mortality, kidney failure, cardiovascular disease, mineral bone disorder, and poor nutrition ***(Becherucci et al., 2016).***

Although the underlying problem that initiated chronic kidney disease often cannot be treated primarily. The progression in chronic renal disease may be largely due to secondary factors that are unrelated to the activity of the initial disease. These include anemia, osteodystrophy, systemic and intraglomerular hypertension, glomerular hypertrophy,

proteinuria, metabolic acidosis, hyperlipidemia, tubulointerstitial disease, systemic inflammation, and altered prostanoid metabolism. This common sequence of events in diverse types of chronic kidney disease is the basis for the common management plan for children with chronic kidney disease, irrespective of the etiology ***(Ahn, Kang, Ha, 2021).***

In a National Health and Nutrition Examination Survey (NHANES) on the prevalence of chronic kidney disease in adolescents aged 12-18 years, the authors observed that the prevalence of persistent albuminuria was similar between 1988 and 2014 and ranged from 3.29% to 3.26%. However the prevalence of both reduced and low (estimated glomerular filtration rates) eGFRs was higher in the most recent study period ***(Saydah et al., 2018).***

Primary kidney disease is an important predictor of CKD progression in children. Congenital anomalies of the kidney and urinary tract (CAKUT) are the most common cause of pediatric CKD. Children with CAKUT experience a slower progression of CKD than those with other causes, resulting in a lower proportion of CAKUT in the population of children with kidney failure. Glomerulopathy in children is a result of various disorders including genetic and autoimmune diseases. It causes inflammation and damage to the glomeruli, the filtering units of the kidney, resulting in a rapid decrease in kidney function ***(Ahn, Kang, Ha, 2021***).

CKD in children is suspected clinically either through typical clinical syndrome or with isolated clinical feature in the form of short stature, poor appetite, growth failure, anemia, bone deformities, generalized fatigue, lack of energy, edema, seizures, dyspnea, hearing loss, recurrent infections or through routine screening with urine, serum chemistry, or imaging of genitourinary system. At times patients may present with symptoms of gross hematuria, flank pain, low urine output, persistent pyuria, polyuria, incontinence, poor urine stream, urgency and nocturia ***(Tuttle et al., 2019)***. Anemia is a common complication of CKD and is associated with several clinical consequences, including mortality, cardiovascular morbidity, and growth failure ***(Kim et al., 2020).***

Treatment of chronic kidney disease should include the following: specific therapy based on diagnosis, evaluation and management of reversible causes of renal dysfunction, prevention and treatment of complications of decreased kidney function (eg, anemia, bone disease, cardiovascular manifestations, hypertension, growth failure, evaluation and management of comorbid condition, slowing the loss of kidney function, preparation for kidney failure therapy, replacement of kidney function with dialysis and

transplantation if signs and symptoms of uremia are present, management of complications***(Gulati et al., 2021).***

Both children with Chronic Kidney Disease and their families have to deal with various medical procedures on a daily basis. Taking care of a child with chronic kidney disease has a significant impact on the family's dynamics and functioning, and it is generally agreed that these children's parents experience more stress than the parents of healthy children. The family is confronted with new demands, changes and constant readjustments. However, these difficulties can be alleviated by the support of health care professionals, particularly nurses ***(Wong, 2014).***

Significance of the study

Total children attended in the pediatric nephrology clinic of at Ain shams university children hospital and the pediatric conservative nephrology clinic of the pediatric dialysis unite at Ain shams university children hospital in 2017 were 236 children (***pediatric hospital statistical office, data base,2017).***

Community health nurse play a pivotal role in the management of children with CKD. Helping and enabling children and their family to be aware of their condition, and educating them to make informed decisions about long-term treatment is thought to be beneficial. Enhancing self-management can be achieved by, educating children and their family on the importance of blood pressure control ensuring they are aware that reducing raised blood pressure is a key factor in preventing progression of CKD. Encourage home blood pressure monitoring where appropriate. Education on maintaining a good glycemic control to slow progression of CKD. Advice on healthy eating and exercise ***(Chronic Kidney Disease Clinical Nurse Specialist, 2014)***

Aim of the study

The aim of this study was to assess the mothers' care of their children with Chronic Kidney Disease through:

1- Assessing Mothers knowledge regarding Chronic Kidney Disease.

2- Assessing mother's reported practices regarding their care for Chronic Kidney Disease.

Research questions

1- What are the mothers' knowledge regarding Chronic Kidney Disease?

2- What are the mothers' reported practices regarding care of their children suffering from Chronic Kidney Disease?

3- Is there relation between mothers' knowledge and their reported practices regarding care of their children suffering from Chronic Kidney Disease?

Subjects and Methods

Research design:

Descriptive analytical research design was utilized to fulfill the aim of this study.

1-Technical Design:

A-Research Setting:

The study was conducted in Nephrology clinic, and the pediatric conservative nephrology clinic of the pediatric dialysis unit at Pediatric Hospital affiliated at Ain Shams University hospitals in Egypt because it was Pediatric 's university hospital and one of the major hospitals that provides health care for all governorates in Egypt.

Sampling:

Sample size:

A purposive sample was used for choosing the study subjects. Study subjects include a representative of total children in nephrology outpatient clinic attendance rate (N=236) at Pediatric 's Hospital, Ain Shams University; Based on sample size equation 75children will be participated in the study. So, the sample size was calculated by adjusting the power of the test to 80% and the confidence interval to 70% with margin of error accepted adjusted to 5% and a known total population of 75 children using the following equation ***(Chow et al., 2017).***

$$n = \frac{N \times p(1-p)}{[N-1 \times (d^2 \div z^2)] + p(1-p)]}$$

$$75 = \frac{236 \times 0.50(1-0.50)}{[236-1 \times (0.05^2 \div 1.04^2)] + 0.50(1-0.50)]}$$

1. N= Community size
2. z= Class standard corresponding to the level of significance equal to 0.70 and 1.04 d= The error rate is equal to 0.05
3. p= Ratio provides a neutral property = 0.5

The sample size was 75 mothers of children diagnosed with chronic kidney disease, children attended the nephrology outpatient clinic, who diagnosed with chronic kidney disease where follow-up and medical treatment are carried out in the previously mentioned setting. The study sample was chosen according to the following inclusion criteria: all available children aged from 2 years to 12 years diagnostic with chronic kidney disease. both gender and attending with their mothers

It was a non-probability sample that was selected based on criteria and agreement to participate in the study. Where cases were selected until the specified number of the sample is completed.

B- Data collection tools:

One tool was used for data collection to conduct this study.

An interviewing questionnaire:

It was designed by the researchers in Arabic language and it contains three parts as follow:

Part I: A-Socio-demographic characteristics of the children suffering from Chronic Kidney disease. (sex, age, education level and children ranking between his siblings)

B-Socio-demographic characteristics of their mothers **(**age, educational level, occupation,

number of family members, number of house room, and crowding index)

Crowding index was calculated by using the following equation ***(Nessim, 2016):***

CI NO of family members

NO of home's rooms

Crowding index was categorized as follow**:-**

Fair (up to 2)

Crowded (2 up to 3)

Very crowded (3 or more)

:

Part II: Designing to assess mothers' knowledge

Mother's knowledge about chronic kidney disease **(**Meaning of chronic kidney disease, reasons for chronic kidney diseases, signs and symptoms of chronic kidney diseases, diagnosis of chronic kidney disease, complications of chronic kidney disease, Treatment steps of chronic kidney disease, Purpose of treatment, the child should go to the doctor in case of, and Source of information you have about chronic kidney disease).

Scoring System of knowledge:

The scoring system was adopted with rating ranging from 1 to 2 with a higher score reflecting a satisfied for each item. Each question response was either satisfied (2 grade) or unsatisfied (1 grade) where the higher score indicates that the mothers had satisfied knowledge about congenital heart diseases.

Score % = (the observed score / the maximum score) × 100.

Knowledge comprises of 18 items and total score ranging 18-36 grades:

- Satisfactory Knowledge >50%
- Unsatisfactory Knowledge ≥50%

Part III: Designing to assess Mother's reported practices:

Mother's reported practices related to care of their children with. chronic kidney disease (Proper nutrition, Physical activities, Dealing with the symptoms of the disease and Regular follow up and treatment).

Scoring system of practices:

The scoring system was adopted with rating ranging from 1 to 3. Each question response was either always (3 grade), sometime (2 grade) and never (1 grade), where the higher score indicates that the mothers correctly done with health problems in their children.

Score % = (the observed score / the maximum score) × 100

Practice comprises of 52 items and total score ranging 52-156 grades:

- Adequate ≥60%
- Inadequate <60%

Tools' validity:

The tools were tested and evaluated for their face and Content validity and reliability. Face and Content validity were performed by two expert in Community Health Nursing Department of Faculty of Nursing and one professor of the Nephrology Department in

Pediatric Department, Faculty of Medicine, Ain Shams University, Egypt; they reviewed the tools for content accuracy.

The developed tools were modified according to the expert 'opinion; this modifications were in the form of omission or addition of some questions or rephrasing of some statement.

Tools reliability:

The internal consistency was measured to identify the extent to which the items of the tools measure the same concepts and correlate with each other by using alpha Cronbach's test for reliability test – retest was done (0.887).

Administration Design:

An official approval was obtained to carry out the study that issued from the faculty of nursing, Ain shams university to the director of pediatric affiliated to Ain Shams University Hospital).

Ethical consideration:

Ethical approval was obtained from the scientific ethical committee of Faculty of Nursing, Ain Shams University. In the addition, written consent was obtained from every participant who agreed to share in the study. They were assured that anonymity and confidentiality would be guaranteed and the right to withdraw from the study at any time.

Pilot Study:

The Pilot Study was carried out on 8 children to ensure the clarity of questions, applicability of the tools and the time needed to fill the questionnaires.

According to the result obtained the necessary modification was done and excluded from the study sample.

Field Work:

The researcher interviewed the mothers and their children in Pediatric Nephrology Clinics at Ain Shams University pediatric Hospital. And the pediatric conservative nephrology clinic of the pediatric dialysis unites at Ain shams university children hospital, introduce herself to mothers, briefly explained the study objective with the kind of questions and gives guidance if needed to answer the questions. Data collection was carried out in the period from August 2021up to October 2021. The mothers were interviewed in the previous setting 2 days per week (Saturday and Monday). The researcher visited pre mentioned setting Pediatric Nephrology Clinics and pediatric conservative nephrology clinic daytime to collect data from 9:00 am to 1:00 pm.

Statistical design

The collected data were organized, coded, tabulated and analyzed by using appropriate statistical test as "Chi square", T test for comparing between related sample, and R test for number and percentage distribution, by using the Statistical Package for Social Science (SPSS), version 23 to determine if there were statistically significant relations. P- Value = less than 0.05 was considered significant

and less than 0.001 was considered as highly significant.

Results

Table (1): Distribution of the children suffering from chronic kidney disease according to their characteristics (n=75).

Item	No.	%
Age (years):		
4-<6 years	24	32.0
6-<8 years	19	25.3
8-<10 years	21	28.0
10-≤12 years	11	14.7
$\bar{x}$ ±SD	7.51±1.13	
Sex		
Male	43	57.3
Female	32	42.7
Ranking of child in the family		
First	37	49.3
Second	15	20.0
Third	11	14.7
Fourth and above	12	16.0
Education Level:		
Pre-kindergarten preparatory	4	5.3
Primary	39	52.0
Preparatory	19	25.3
Secondary	13	17.3

Table (1):- This table illustrates that, the mean age of studied children is 7.51±1.13 years old, whenever 57.3% regard male. 49.3% of the studied children ranking as first, while 52% have primary education.

Table (2): Distribution of the mothers according to their characteristics (n=75).

Items:-	No.	%
Age (years)		
20-<30 years	20	26.7
30-<35 years	24	32.0
35-<40 years	13	17.3
40-<45 years	11	14.7
45-<50 years	5	6.7
≥50 years	2	2.7
$\bar{x}$ ±SD	35.20±5.28	
Education Level:		
Doesn't read and write	16	21.3
Reads and writes	9	12.0
Primary	9	12.0
Preparatory	14	18.7
Secondary	10	13.3
University	17	22.7
Postgraduate	0	0.0
Occupation:		
Government employee	21	28.0
Pensioner	0	0.0
Private sector	17	22.7
Housewife	32	42.7
Artisan	5	6.7

Table (2): This table explains that, the mean age of studied mothers is 35.20±5.28 years old, whenever 22.7% have university education And 42.7% of them were housewife.

Table (3): Distribution of the studied mothers according to their satisfactory level of knowledge about chronic kidney disease of mothers (n=75).

Third: knowledge mother has on chronic kidney diseases	No.	%
Meaning of Chronic kidney diseases	27	36
Reasons for chronic kidney diseases	22	29.3
Signs and symptoms of chronic kidney diseases	30	40
Diagnosis of chronic kidney diseases	17	22
Complications of chronic kidney diseases	29	38.6
Treatment steps of chronic kidney diseases	34	41.3
Purpose of treatment	33	37.3
The child should go to the doctor in case	28	37.3

Table (3):- this table shows that regarding the mother's knowledge about chronic kidney disease, this table clarifies that, less than half (36%, 29.3%, 40%, 38.6%, 41.3%, 37.3% and 37.3%)of mother scored satisfactory knowledge as regarding meaning of chronic kidney diseases, reasons for chronic kidney diseases, signs and symptoms of chronic kidney diseases, complications of chronic kidney diseases, treatment steps of chronic kidney diseases, purpose of treatment and the child should go to the doctor in case.

Fig (1):- Source of information about chronic kidney diseases.

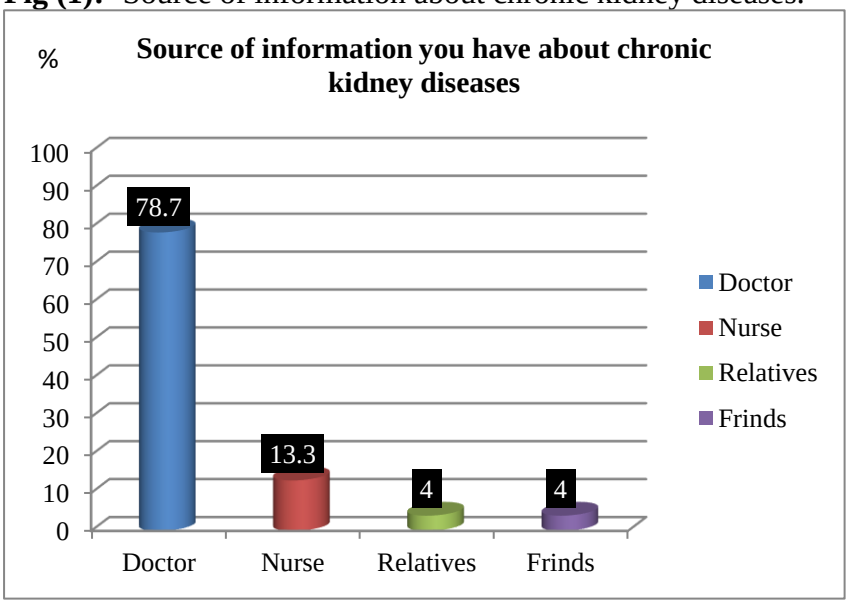

Fig.(1):- this fig views that, 78.7% of mothers had their knowledge from doctor, while, 13.3% had their knowledge from nurse. Moreover, 4% had their knowledge from relative. On the other hand, 4% had their knowledge from friends.

Fig. (2): Distribution of the studied mothers according to their total level of practices towards the care of their children suffering from chronic kidney diseases.

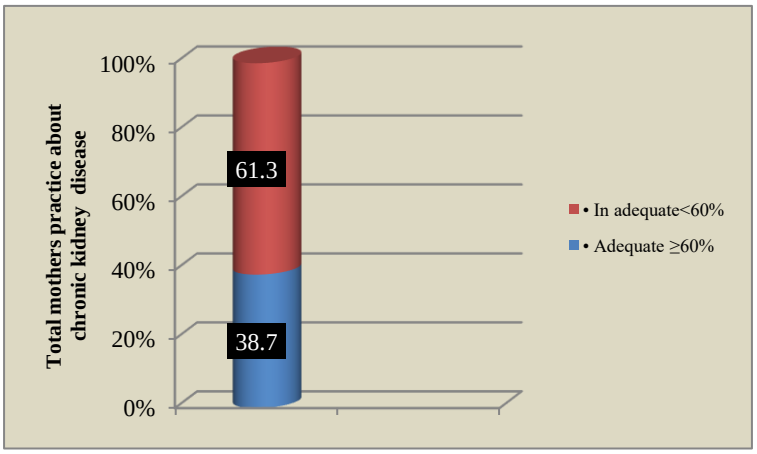

Fig. (2): clarifies that 61.3% of mothers had inadequate level of practices towards the care of their children suffering from chronic kidney diseases.

Table (4):- Correlation between studied mother's knowledge and total score of practice about care of their children suffering from chronic kidney diseases (N=75).

		Total score of knowledge	Total score of practice
Total score of knowledge	**r-value**		0.050
	p-value		0.862
Total score of practice	**r-value**	0.050	
	p-value	0.862	

r-Pearson Correlation Coefficient
***Highly statistical significant correlation (p<0.001).*
**A statistical significant correlation (p<0.05)*

Table (4):- This table shows that no correlation between total studied of mother's knowledge, total score of practice about care of their children suffering from chronic kidney diseases and there is no statistically significant correlations with (p-value >0.05 NS).

Discussion

CKD is a clinical syndrome characterized by a gradual irreversible loss of kidney function that can further progress to end stage kidney disease. Childhood CKD presents clinical features such as growth failure and psychosocial issues that significantly impact quality of life. Cardiovascular complications secondary to CKD lead to morbidity in young adulthood. Children with CKD pose unique challenges to the health system and their providers who must address the primary kidney disorder as well as the many extra-renal manifestations that complicate management ***(Amanullah et al., 2022).***

Concerning children characteristics, the present study revealed that, the mean age of studied children is 7.51±1.13 years old, this might be related to that, most common age among children for chronic kidney disease is 5-12 years ***(Kaspar et al., 2016)***. This study in agreement with ***Darwish et al., (2020)*** who mentioned that more than one third of studied children their age group was (8-18 years), this result in disagreement with ***Eydivandi et al., (2021)*** who reported that studied children' mean±SD age was 9.85±1.22.

The current study stated that, more than half of studied children were males. This finding on line with ***Yauba et al., (2017)*** who revealed that more than half of studied children were males. this study was disagreed with ***Piran et al., (2017)*** who proved that two thirds of studied children were females.

The present study stated that, about half of studied children ranking as first, This result in disagreement with ***Welliam et al., (2016)*** who found that more than one third of studied children ranking as first.

The constant study reported that, more than half of studied children had primary education, in the researcher point of view, this might be related to more than two thirds of studied children their age less than 10 years. This study supported by ***El Shafei et al., (2018)*** who reported that more than two thirds of studied children had primary education. Contrariwise, this result in agreement with ***Pardede et al., (2019)*** who stated that more than one quarter of studied children had primary education.

Regarding mothers' sociodemographic data, the current study proved that, the mean age of studied mothers is 35.20±5.28 years old. This finding in agreement with ***El Nagar et al., (2020)*** who mentioned that the mean±SD age of studied mothers was 34.92±6.06 years old. Also, This result was agreed with ***Mahmoud et al., (2021)*** who revealed that the mean±SD age of studied mothers was 38.50 ± 7.21 years old.

The present study reported that, less than one quarter of studied mothers had university education. This study on line with ***Hassan &***

Mahmoud, (2019) who stated that less than one quarter of studied mothers had university education. Contrariwise, this result in disagreement with ***Didsbury et al., (2022)***.

The constant study mentioned that, more than one third of studied mothers were housewife. This study in agreement with ***Abdalla et al., (2020)*** who stated that more than two thirds of studied mothers were housewife. Also, this finding was agreed with ***Dem & Hoai, (2020)*** who proved that more than half of studied mothers were housewife.

Concerning mothers 'satisfactory level of knowledge about chronic kidney disease of mothers, the constant study revealed that, more than one quarter of mothers had satisfactory knowledge about meaning and causes of CKD and less than half knew the signs and symptoms, and determine complication of CKD, and less than half able to determine their treatment of CKD, this result supported by ***Milenia et al., (2022)who*** mention that knowledge of mothers about their children's illness was definitely poor. From the researcher point of view that the mothers studied depended on the doctors only to get the information about their children's disease and they didn't read about the disease.

Regarding mothers' source of information, the constant study found that, more than three quarter of mothers had their knowledge from doctor, less than one quarter of them had their knowledge from nurse and a minority of them had their knowledge from relative and friends. This study in disagreement with ***Milenia et al., (2022)*** who mentioned that more than one third of studied Mother's gain their knowledge regarding kidney diseases from doctors while more than half of them acquired their knowledge from friends and relatives, this might be related to differences in education level.

Regarding correlation between studied mother's knowledge, total score of practice, total score of health problems and total score of health needs in pre-program about care of their children suffer from chronic kidney diseases, the constant study reported that, there was no correlation between total studied of mothers' knowledge, total score of practice, total score of health problems and total score of health needs in pre-program about care of their children suffer from chronic kidney diseases.

The present study revealed that more than half the of the studied mothers had inadequate total reported practices about chronic kidney diseases**,** this result was agreement with ***El Nagar et al., (2020)*** who reported that Children with CKD require more repeated care.

From the researcher's point of view this might be due to low mothers' knowledge about chronic

kidney diseases that affected their practices regarding the care of their children suffering from chronic kidney diseases.

This study in disagreement with ***Bassam & Nassar, (2021)*** who mentioned that there was positive correlation between total studied mothers' knowledge and practice pre-program. Also, this finding was disagreed with ***Pourghaznein et al., (2022)*** who proved that there was positive correlation between children health problems and their needs

Conclusion

The current study indicated that, more than half of studied children with chronic kidney diseases were female. Majority of mothers had unsatisfactory knowledge about chronic kidney diseases and its treatment, as well as less than two thirds of them, had inadequate level of total practices about the care provided for their children with chronic kidney diseases , the result of the study proved that there was no significant correlation between the total mothers' knowledge about chronic kidney diseases among studied children and reported practices regarding the care of children suffering from chronic kidney diseases..

Recommendations

Based on the findings of this study, the following recommendations were suggested:

1- Periodic counseling program should be done to all mothers of children suffering from chronic kidney disease who attended to the outpatient clinics about diseases treatment, prevention and control measures.
2- Doctors and Nurses Encourage support group of mothers having children with chronic kidney diseases to work as a volunteer in the consulting unites to help the mothers of children with chronic kidney diseases newly diagnosed cases to be oriented with the health needs and problems of their children and how to care with them.

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