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EFFECT OF FAMILY CENTERED CARE BASED INTERVENTION ON IMPROVING QUALITY OF CHILDREN'S LIFE WITH CHRONIC KIDNEY DISEASES

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Abstract

Background: Family centered care (FCC) is a holistic approach for planning, delivering, and evaluating mutually beneficial partnerships among families and healthcare providers. Children with chronic kidney diseases (CKD) have elevated health care needs and often experience physical, emotional, and social difficulties which negatively affect their quality of life. **Aim:** This study aimed to evaluate the effect of family-centered care-based intervention on improving quality of children's life with chronic kidney diseases. **Research design:** A quasi-experimental research design was utilized in this study. **Setting:** This study was conducted at pediatric inpatient and outpatient departments affiliated to Suez Canal University Hospital and General Ismailia Hospital, affiliated to Comprehensive Health Insurance/Egypt. **Sample:** Non probability convenience sample involved 45 children suffering from CKD of both gender, aged between 1-18 years (with the exclusion of children suffering from other chronic illness, either medical or mental). All available family caregivers accompanying their children were involved regardless of their characteristics. **Tool** (1) The pre designed questionnaire, (2) the index of family caregivers' participation, (3) observational checklist, (4) quality of life scale and the family centered care scale were used pre/post FCC based intervention. **Results:** There was a highly statistically significant relation ($P<0.001$) between the core concept of family centered care of the studied family caregivers and the total QoL of their children post family centered care based intervention. **Conclusion:** The family centered care intervention had a positive effect on improving the quality of life of children with chronic kidney diseases. **Recommendation:** Include family centered care approach in care of children suffering from CKD.

Keywords: Chronic Kidney Diseases, Family Centered Care, Quality of Life, Pediatric Nursing.

INTRODUCTION

Family-centered care in pediatric nursing is an approach that recognizes the family as an essential and active partner in a child's care, incorporating their perspectives, values, and strengths into the healthcare process. This approach acknowledges that the family is a critical influence on a child's well-being and that their involvement is vital for achieving positive outcomes. Pediatric nurses need to be empowered to promote family centered care (Johnson, 2023).

The Institute for Patient and Family-Centered Care (IPFCC) recommendation's which are respect, dignity, information sharing, participation in care and decision-making, collaboration among children, families and the healthcare team. FCC was implemented for the care of children by the healthcare professionals, which provides positive results for families and children by meeting their needs (Cetintas et al., 2021).

Chronic kidney disease (CKD) constitutes a major health challenge, with a global prevalence of 15–74.7 cases /million children. Preventing CKD in children, slowing its progression and management of complications are essential, especially in challenged health systems in low middle-income countries (Amanullah et al., 2022).

Kidney Disease: Improving Global Outcome (KDIGO) guidelines define CKD as either kidney damage or a decreased glomerular filtration rate (GFR) of less than 60 mL/min/1.73 m2 for at least 3 months. Whatever the underlying etiology, once the loss of nephrons and reduction of functional renal mass reaches a certain point, the remaining nephrons begin a process of irreversible sclerosis that leads to a progressive decline in the GFR (Kidney Disease: Improving Global Outcomes (KDIGO), 2024).

Worldwide, 11–13% of the overall world's population suffers from chronic kidney disease. Congenital anomalies of the kidney and urinary tract (CAKUT) constitute the most common cause of pediatric CKD (48–59%) (Masalskienė et al., 2021). The incidence of chronic kidney disease in Egypt is greater in males than in females because of the higher frequency of congenital abnormalities of the kidney and urinary tract in males (Arab Republic of Egypt, Ministry of Health, National Information Center for Health, 2019).

Children with chronic kidney diseases often experience physical, emotional, and social difficulties which affect on their quality of life, while their families navigate the complexities of caregiving, financial strain, and emotional stress. Benefits of FCC include families who feel supported and informed are more likely to follow treatment regimens consistently, leading to better disease management and improve their quality of life. Families report greater satisfaction with healthcare services when they are treated as active partners in their child's care (Gayel, 2024).

Aim of the Study

This study aimed to evaluate the effect of family centered care-based intervention on improving quality of children's life with chronic kidney diseases.

Research Hypothesis:

There will be a positive effect of family centered care based intervention on improving quality of children's life with chronic kidney diseases.

SUBJECTS AND METHODS

Research design:

A quasi-experimental design was used in the study.

Setting:

This study was conducted at both pediatric inpatient and outpatient departments affiliated with Suez Canal University Hospital, General Ismailia Hospital, affiliated with Comprehensive Health Insurance / Egypt.

Sampling technique:

Sample size:

The sample size of 45 children having chronic kidney disease and their parents was calculated using the following formula:

$$n = \frac{Z^2 * P\,(1 - p)}{E^2}$$

Where n = sample size

Z = statistic for a level of confidence = 95% Z = 1.96

P = Estimated proportion = 0.03 (3% prevalence of CKD in children). Due to the number of children with CKD, on average, 20 are admitted each month from a total of 600 cases at the inpatient department and outpatient clinic of pediatric patients.

E = desire margin of error = 0.05

$$n = \frac{(1.96)^2 * (0.03) * (0.97)}{(0.05)^2}$$

$$n = \frac{3.8416 * 0.0291}{0.0025} = 45$$

Type of sampling:

Non probability convenience sampling method was used in this study.

Tools of data collection:

I- Pre-designed questionnaire (pre/post) that was designed by the researcher, after reviewing relevant literature, was written in simple Arabic language in close ended questions, and consisted of the following parts:

Part one:

It was concerned with characteristics of both children and their family caregivers to gather data in relation to:

A) Characteristics of the studied children (age, gender, level of education and ranking in the family).

B) The studied children’s medical history (diagnosis, duration of illness, clinical manifestations, number & frequency of hospital admissions, present health status, complications, and medications).

C) Characteristics of the studied family caregivers (age, level of education, occupation and type of work).

Part two:

This part was concerned with data related to assessing the studied family caregivers' knowledge regarding chronic kidney diseases (definition, causes, clinical manifestations, treatment, care and complication) and family centered care, (definition, principals, benefits and needs of families).

Scoring system:

As regards family caregivers' knowledge regarding CKD and FCC (pre/post FCC based intervention), the family caregivers' answer was evaluated by using a model key answer. The score of each question was zero if the answer, I don't know or incorrect, one score if incomplete and correct answer and two score if the answer was completely correct. The total knowledge level was classified as poor knowledge (< 50%) fair knowledge (50<75%) and good knowledge (≥75%).

II-The Index of parents' participation (pre/post FCC):

The index was adapted from Abdelkader, et al., (2016) and Romaniuk, (2009) to assess the level of family caregivers' participation in child care during hospitalization. It consisted of forty items, including four categories: Activities of daily living (ADL) (eight items), psychological support (nine items), supportive care, diagnostic procedures, and treatment (eight items), and some activities of nursing care (fifteen items).

Scoring system:

The family caregivers' participation in care of their children during hospitalization was checked with a two-point scale (Zero if No & One if Yes). The total percentage was 100%, where higher mean scores indicate higher family caregivers' participation. It was categorized as the following: minimum (<50%), moderate (50<75%) and maximum level of family caregivers' participation (≥75 %)

III. Observational Checklists (Pre/Post FCC based intervention):

Observational checklists were adopted from Hockenberry & Wilson, (2018) and Potter et al. (2012) to assess the actual practices of family caregivers as regards, physical assessment (body weight, input & output fluid balance, A/V fistula's care, hand washing, oral medication and cold compresses), (body temperature measurement orally and axillary), assessment of vital signs; pulse, respiration, blood pressure.

Scoring system:

Scoring system for family caregivers' actual practices was allocated as two grades given for each step done correctly and one grade for each step done incompelete, and zero for not done. Accordingly, the family caregivers' total actual practices were categorized into either incompetent (<75%) or competent (≥ 75%).

IV. Quality of life inventory scale (QoL) (Pre/Post FCC based intervention):

The quality of life inventory scale was adopted from Varni, et al., (2001). It was used to determine the level of quality of life for children suffering from CKD and it was composed of five items (physical, social, psychological, school functioning, and general well-being).

Scoring system:

Quality of life scale consisted of five items in each scale (physical, social, psychological, school functioning and general wellbeing). The scores ranged from 0-4 with zero representing never has problem, with (1) representing rarely has problem, (2) representing sometimes has problem, (3) representing often has a problem and (4) representing almost always has a problem.

The items of the five sub scales of the QoL for children with chronic kidney diseases was classified according to their responses into high (≥75), moderate (50<75%), and low (< 50%).

V. The Family Centered Scale (FCCS) for parents (Pre/Post FCC based intervention):

This scale was adopted from Gill et al., (2014) and Shield et al., (2004) that was used to assess family caregivers' knowledge regarding core concept of FCC. The FCCS consisted of sixteen items that were divided into four subgroups (core concepts). Respect included three items (6,9,13) information sharing, included four items (4,8,10,15), collaboration included four items (2,3,11,12) and support of family included five items (1,5,7,14,16).

Scoring system:

The family caregivers’ responses of FCCS items were scored using a three Likert type rating scale ranging from disagree (0 point), somewhat agree (1 point) and agree (2 points). Negative statements items 4,6,12,16 were reverse coded before calculating the scores. Total score varies between 0-32. The higher mean score indicated a higher level of agreement on statement (good knowledge for core concept of FCC) and vice versa.

VI. The family centered care based intervention was conducted through eight sessions

Different teaching method (lecture, group discussion, demonstration/ redemonstration and role play& scenario) and teaching media (handout, pictures, PowerPoint, video film and real objects) were used. The first four sessions were covering the theoretical part and the other four sessions for the practical part of FCC based intervention that divided as the following:

The theoretical part of the first session, concerned with knowledge about the FCC’s core concept and its benefits, the second session included knowledge about chronic kidney diseases, including anatomy and physiology of the kidney, definition, causes, classification, clinical manifestations, and management.

The third session concerned with knowledge regarding nutrition and laboratory tests and their normal values. The fourth session included knowledge about hemodialysis and peritoneal dialysis.

The practical part of the fifth educational session, concerned with a competent practice regarding care for children with CKD, including hand hygiene, body temperature assessment (oral and axillary), cold compresses, measurement of vital signs (pulse, respiration, and blood pressure).

The sixth session included practice regarding measurement of body weight, oral medication, A/V fistula care. The Seventh session concerned with practice regarding care for children before and after hemodialysis session, measurement of intake & output balance. The eighth session included practice regarding care peritoneal dialysis.

Administrative design:

Administrative approval to carry out the study was done from administrators of the study setting through an issued letter from Dean of Faculty of Nursing of Suez Canal University and Comprehensive Health Insurance/Egypt.

III- Ethical consideration

An official permission to conduct the proposed study was obtained from the Scientific Research Ethics Committee affiliated to the Faculty of Nursing, Suez Canal University, on 31/10/2022 with number (179).

Participation in the study was voluntary, and subjects were given complete information about the study and their role before signing the verbal or written consent. The ethical considerations included explaining the purpose and nature of the study, stating the possibility of withdrawal at any time, and confidentiality of the information for research purposes only.

B- Pilot study:

The pilot study was conducted involving 10% of the studied children and their family caregivers (5 children with their family caregivers) to test the feasibility of the tools and the time consumed for filling in the study and tools also to test the language clarity. The studied children included in the pilot study were excluded later from the study sample.

Data obtained from the pilot study were revised and analyzed then the necessary modification were done. The time concerned to fill in the tools took about 45 minutes for each study subject.

Field work:

The actual field work took about 6 months from the first week of February up to the end of August (2023). The setting at pediatric department in the third floor, which contain 6 rooms and each room contain 6 beds and hemodialysis unit at the previously mentioned setting. The researcher explained the purpose of the study to the family caregivers and their children if their age permitted before starting the interview, where each family caregiver and their children suffering from CKD were interviewed individually. The researcher was available in the study setting two days/ week at the morning shift (8 am to 1 pm from Sunday to Tuesday).

RESULTS

Table (1): Number and percentage distribution of the studied children according to their characteristics (n=45)

Items	No.	%
Age/years		
1:<6	10	22
6:<12	20	**45**
12:≤18	15	33
$\overline{X}$ ±SD	**9.67±1.84**	
Gender		
Male	26	**57.7**
Female	19	42.3
Educational level		
Not yet enrolled	3	6.7
Nursery school	5	11.1
Elementary phase	12	26.7
Secondary phase	15	**33.3**
Dropped out of education	10	22.2.
Ranking		
First	20	**44.4**
Second	12	26.7
Third	10	22.2
Fourth	3	6.7
Residence		
Urban	6	13.3
Rural	39	**86.7**
Family size/member		
≤3	4	9
3:<5	25	**56**
5:<7	11	24
≥7	5	11
$\overline{X}$ ±SD	**5.00±1.00**	

Table (2): Distribution of the studied children according to their physical characteristics (n=45)

Results	Physical characteristics					
	Weight		Height		BMI	
	No	%	No	%	No	%
Low/ shorter than average (< 3rd percentile)	7	15.6	24	**53.3**	8	17.8
Normal (3rd >97th percentile)	14	31.1	21	46.7	17	37.8
Abnormal/over (≥ 97th percentile)	24	**53.3**	-	-	20	**44.4**

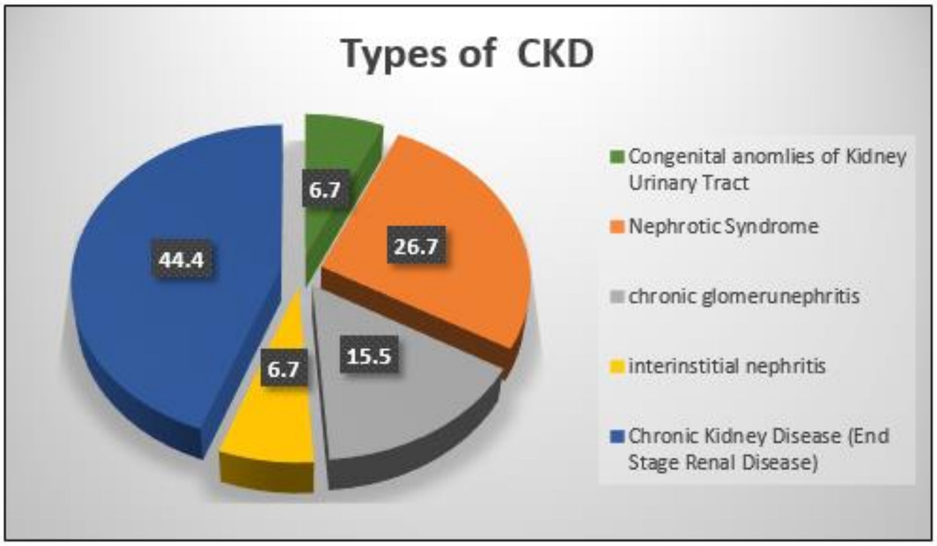

Figure (1): Percentage distribution of the studied children according to the type of CKD

Table (3): Distribution of the studied family caregivers according to their characteristics (n=45)

Characteristics	No.	%
Age in years		
20 < 25	6	13.3
25:<35	17	**37.8**
35:<45	14	31.1
≥ 45	8	17.8
$\overline{X}\underline{+}$SD	**35.33±6.71**	
Educational level		
Illiterate	19	**42.2**
Primary	11	24.5
Technical	9	20
High	6	13.3
Occupation		
Yes	5	11.1
No	40	**88.9**

Table (4): Number and percentage distribution of the studied family care givers' according to their total knowledge level about CKD and FCC pre/post FCC based intervention (n=45)

Total Knowledge of CKD &FCC	Pre		Post		X^2	p-value
	No	%	No	%		
Poor ≤ 50	32	71.1	11	24.4	20.578	0.001**
Fair (50-75%)	7	15.6	24	53.4		
Good ≥ 75%	6	13.3	10	22.2		

Using: Chi-square test & Fisher's Exact test
*p-value >0.05 NS; *p-value <0.05 S; **p-value <0.001 HS*

Table (5): Distribution of the studied family caregivers' total actual practices level regarding care of their children with CKD pre/post FCC based intervention (n=45)

Studied family caregivers' total actual practice level	Pre		Post		X^2	p-value
	No	%	No	%		
Incompetent (<75%)	28	62.2	8	17.8	16.713	**0.001****
Competent (≥ 75%)	17	37.8	37	82.2		

Using: Chi-square test & Fisher's Exact test
*p-value >0.05 NS; *p-value <0.05 S; **p-value <0.001 HS*

Table (6): Comparison between the total mean scores of the studied family caregivers' knowledge regarding the index of family caregivers' participation in the child care during hospitalization pre/post FCC based intervention (n=45)

The Index of family caregivers' participation	Pre intervention	Post intervention	Paired t-test	p. value
	$\bar{X}\pm SD$	$\bar{X}\pm SD$		
Activities of daily living	40.63±6.99	45.00±0.00	5.326	**0.001****
Psychological support	37.88±6.35	43.89±0.89	6.288	**0.001****
Supportive care	32.88±9.36	41.25±2.66	5.770	**0.001****
Activities of nursing care	23.53±10.60	38.73±2.99	9.258	**0.001****
Total	28.44±7.75	36.95±1.89	7.156	**0.001****

*p-value >0.05 NS; *p-value <0.05 S; **p-value <0.001 HS*

Table (7): Comparison between the total mean score of the studied family caregivers' knowledge regarding the core concept of family centered care pre / post FCC based intervention (n=45)

Studied family caregivers' knowledge regarding the core concept of FCC	Pre intervention	Post intervention	Paired t-test	p-value
	$\bar{X}\pm SD$	$\bar{X}\pm SD$		
Respect	34.00±8.72	88.33±2.89	39.673	**0.001****
Information sharing	35.75±8.77	84.50±3.00	35.282	**0.001****
Collaboration	44.25±15.59	89.25±4.11	18.723	**0.001****
Support of family	35.20±11.93	85.60±3.85	26.970	**0.001****
Total	37.30±11.25	86.92±3.46	28.280	**0.001****

*p-value >0.05 NS; *p-value <0.05 S; **p-value <0.001 HS*

Table (8): Number and percentage distribution of the studied children according to their total quality of life domains pre/post FCC based intervention (n=45)

Total quality of life domains	Pre		Post		χ2	p-value
	No.	%	No.	%		
High QOL	12	26.6	22	48.9	7.151	**0.028***
Moderate QOL	13	28.9	14	31.1		
Low QOL	20	44.5	9	20		

Using: Chi-square test & Fisher's Exact test
*p-value >0.05 NS; *p-value <0.05 S; **p-value <0.001 HS*

Table (9): Correlation matrix between the studied family caregivers' knowledge regarding the core concept of FCC and the studied children's total quality of life domains pre & post FCC based intervention (n=45)

Pre intervention		**Studied children's total quality of Life domains**
Studied family caregivers' knowledge regarding the core concept of FCC	r-value	0.121
	p-value	0.493
Post intervention		**Studied children's total quality of Life domains**
Studied family caregivers' knowledge regarding the core concept of FCC	r-value	0.664
	p-value	**<0.001****
r-Pearson Correlation Coefficient; **p-value <0.05 significant correlation; **p-value <0.001 highly significant*		

DISCUSSION

Family centered care is a collaborative approach that acknowledges the family as an integral part of a child and the healthcare team. It involves healthcare providers working in partnership with families to make decisions, plan, deliver care, and promote the child's overall well-being (Naz et al., 2023). Therefore, the current study aimed to evaluate the effect of family centered care-based intervention on improving quality of children's life with chronic kidney diseases. Regarding physical characteristics of the studied children (table, 2), the result of the current study showed that more than half of them were overweight. This finding was similar to the study by Abdel-Munaem, (2019), study which entitled" Impact of chronic kidney disease on anthropometric profile, health-related quality of life and cognitive function in children" and found that more than half of the children with CKD were overweight. The finding of the present study illustrated that more than half of the studied children were shorter than average compared to their peers (table, 2). This finding was supported by Darwish et al. (2021), study which entitled "Health-related quality of life in children with chronic kidney disease in Assiut" which found that nearly half of children had short stature.

In the researcher's opinion, these results confirm the negative impact of CKD on the physical characteristics of children that lead to growth failure later. Additionally, children receiving immunosuppressive therapy may develop growth retardation as a result of long-term daily corticosteroid administration, which lead to a negative effect on physical domain of quality of life (Rodig et al., 2018).

The present study (figure, 1) illustrated that near to one third of the studied children had nephrotic syndrome this agreed with Mohammed et al. (2020), study entitled "Effect of mobile-based health education on quality of life among children with chronic kidney diseases during COVID-19 pandemic" who found that one third of the studied children had nephrotic syndrome. In addition, the finding of the present study clarified that near to half of the studied children had chronic kidney disease (ESRD) (figure, 1). This finding was supported by Abd-Alazem et al. (2022), study entitled "Indications and outcome of different dialysis modalities in critically ill children" which found that near to half of children had chronic kidney disease (ESRD). The current study (table, 4) showed that there was a highly significant difference of the studied family caregivers’ total knowledge level about CKD and FCC pre/post FCC based intervention. This result was in an agreement with El Nagar et al. (2020), study which entitled "Empowering mothers caring for their children with chronic kidney diseases through engagement and education" who found that there was an improvement in the mean score of mothers’ total knowledge about CKD and home management in post engagement and education compared to pre engagement and education. The researcher’s think that these results reflect the good awareness of nurses post implementation of FCC can empower the caregivers improvement in the outcomes of management of children suffering from CKD.

As regards actual practices of the studied family caregivers regarding care of their children with CKD, there was a highly statistically significant difference pre/post FCC based intervention (table, 5). This finding is consistent with Abdalla et al. (2019), study which entitled "Empowerment program for mothers to improve quality of life of their children with chronic kidney diseases" who reported that there was a statistically significant difference of total actual practices between pre /post empowerment program.

The present study (table,6) illustrated that there was a highly statistically significant difference in the index of studied family caregivers’ participation regarding CKD pre/post FCC based intervention. This agreed with Wang & Xul, (2020), study which entitled "Effects of family-centered care on children with primary nephrotic syndrome" who reported that statistically significant differences pre/post FCC intervention about mothers' participation in activities of daily living and psychological support, highly statistically significant improvement of mothers' participation in supportive care and nursing care activities post FCC based intervention. From the researcher's point of view, family caregivers of chronically ill children were the most active participants in providing comfort measures and care related to their child’s daily living activities, which reflects the importance of family caregivers’ participation and inner desire to assist in their children care during hospitalization to achieve continuity of home care for their children with CKD when discharged from the hospital.

Concerning the studied family caregivers’ knowledge regarding the core concept of family centered care (table 7), the study results showed that, elevating the mean scores of good knowledge of the studied family caregivers at post FCC based intervention compared to pre FCC based intervention results. This result agreed with Seniwati et al. (2023), study which entitled "Patient and family-centered care for children: a concept analysis" who mentioned that partnership, communication, respect, and compassion as the four attributes of PFCC for children were improved and the implementation of PFCC had a positive impact on children and their families during hospitalization. This result also was in congruence with Wang & Xul, (2020), who mentioned that, improving knowledge of family centered care after intervention reflects better parental satisfaction towards care.

Concerning the studied children’s total quality of life domains (table, 8) there was a highly statistically difference of the studied children pre/post FCC based intervention. This result was congruent with Al-agamy et al. (2022), study which entitled "Effect of an educational intervention based on family centered empowerment model on quality of life of hemodialysis patients and their caregivers" who found that, there was a marked improvement in overall quality of life of the studied caregivers post intervention program with a highly statistically significant difference between pre & post family centered empowerment model. From the researcher's point of view, application of family centered care can increase the QoL of children with chronic kidney diseases. This view supported by Rabiei et al., (2020) study which entitled "Evaluating the effect of family-centered intervention program on care burden and self-efficacy of hemodialysis patient caregivers based on social cognitive theory: a randomized clinical trial study" which mentioned that application the family centered care interventions improved their QoL and well-being.

The researcher thinks that the lower scores of QoL of children with CKD at pre FCC based intervention could be explained by the fact that those children are subjected to numerous short-term and long-term complications related to CKD and its related management therapy that alter their lives, such as frequent hospitalization, painful procedures, school absence, and restrictions in daily living activities that consequently could lead to have a negative emotional impact. The present study (table, 9) revealed that there was a highly statistically significant relation between the studied family caregivers’ core concept of family centered care and the studied children’s total quality of life domains post intervention. The finding agreed with XU &Wang, (2020), study which entitled "Effects of family-centered care on children with primary nephrotic syndrome" who found that there was a significant relation between family centered care and quality of life of children with primary nephrotic syndrome.

The researcher believes that there was a highly statistically significant relation between family caregivers’ core concept of family centered care and quality of life of the children with CKD post FCC based intervention which reflect the necessary application of FCC intervention to improve quality of life of the children with CKD.

CONCLUSION

The family-centered care based intervention had a positive effect on improving quality of children’s life with chronic kidney diseases.

RECOMMENDATIONS

In the light of the findings of the present study, the following recommendations are suggested:

1) Family caregivers should be educated about family-centered care and encourage participation in care for their children suffering from CKD.
2) Periodic monitoring quality of life for children suffering from CKD.
3) Parental involvement in care of their ill children with CKD should be part of the management plan.

4) Designing and carrying out programs for pediatric nurses dealing with children suffering from CKD to promote family-centered care in clinical practice.
5) Further researches are required to determine the barriers / challenges that hinder the implementation of family centered care in pediatric care settings for children suffering from CKD.

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