

Empowering Mothers Caring for their Children with Chronic Kidney Disease through Engagement and Education

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Abstract

Background: Numerous researches have shown that family empowerment interventions are effective for children with CKD as it was associated with improvement in quality of life, self efficacy, disease acceptance and management. As a result, the study aimed to evaluate effect of empowering mothers caring for their children with chronic kidney disease through engagement and education. **Methods:** A quasi-experimental study design using one group pre post test was utilized on a convenience sample composed of 50 mothers and their children who are suffering from CKD and had follow up at kidney center in Aga Central Hospital, Dakahliah, Egypt. Two tools were used for data collection; tool (1) chronic kidney disease knowledge and home management questionnaire that include three parts concerning demographic data, mothers' knowledge and home management for children with CKD. While, tool (2) family Empowerment Scale included three subscales including family, service system and community and political area. **Results:** our findings showed that the mean age of the studied mothers and their children was 34.92 ± 6.06 & 8.34 ± 4.38 respectively. Also, there were a positive relationship between total level of mothers' knowledge, home care of children with CKD and level of family empowerment with statistical significant difference. The mean score of family empowerment sub-scales and total level of family empowerment was developed in the post intervention compared to pre intervention phase. **Conclusion and recommendations:** our study focused on empowering mothers of children with CKD via education and engagement and the findings of our study showed that the level of mothers total knowledge, home care and family empowerment was improved after implementation of empowerment educational intervention. That's why it is recommended that the empowerment educational intervention should be used and implemented for all care givers and their children as a strategy for education and management of CKD.

Keywords: children with chronic kidney disease; empowerment; family engagement, home management

Date of Submission: 30-06-2020

Date of Acceptance: 16-07-2020

I. Introduction

Chronic kidney disease (CKD) for children is considered a major public health problem worldwide. It is a progressive destructive disease that causes irreversible kidney damage and disturbance in fluid and electrolytes and body's metabolism (Safouh, Fadel, Essam, Salah, & Bekhet, 2015). The CKD is an overwhelming disease connected with excessive mortality and cardiovascular morbidity, and specific problems occur in children, for example impaired growth and psychosocial adjustment, which in turn severely affects the quality of life for children and their families. A good recognition of the epidemiology of CKD in children is essential for early identification, recognize preventable or reversible causes of progression, expect prognosis, and help in education of the children and their caregivers (Greenbaum, Warady, & Furth, 2009, and Harambat, Van Stralen, Kim, & Tizard, 2012).

The causes of CKD are very different in children from those in adults. In the United States, and according to recent NAPRTCS report congenital causes, including congenital anomalies of the kidney and urinary tract (CAKUT) (48%) and hereditary nephropathies. Glomerulonephritis accounted for 14% of cases and was the leading cause in children older than 12 years of age (North American Pediatric Renal Transplant Cooperative Study (NAPRTCS) 2008 and Fivush, Jabs, Neu, Sullivan, Feld, Kohaut & Fine, 1998). The incidence of CKD varies in different parts of the world. In most developed countries the incidence varies between 4-10 per million-children below 18 years of age (Maalej, Louati, Guirat, Wali, & Abid2018). In the absence of a national registry, the exact incidence and burden of CKD in children in Egypt is not known.

Children with CKD have need of medical treatment for survival, including hemodialysis and kidney transplantation. The majority of children with CKD are undergoing hemodialysis due to the unavailability of kidneys for transplantation (Talebi, Mohair Lakeh, & Rezasoltani, 2016). Hemodialysis was considered the most common treatment for children with CKD. The families of children are responsible for a major part of the

care and support given to their children and carry a considerable care burden. The care burden is the physical, psychological, and social distress that carries about caring for chronic patients (**Sotoudeh, Pahlavanzadeh, & Alavi, (2019).**

Family centered empowerment is a dynamic, helpful, interactive, and public process help to improve the quality of life of people with chronic disease, responsibility, better interaction with health problem, satisfaction, better response to treatment, prevention of complications, reduced the costs of treatment (**Shahdadi, Rahdar, Mansouri, & Abdollahimohammad, 2018**). Family empowerment is a method through which the families get information and skills in order that it can manage family life ideally and as a result upgrade the family members' lifestyles and quality of life. This type of empowerment, which is realized by the interaction between healthcare professionals and families, brings about a sense of control over family life and leads to positive changes that improve the strengths, abilities, and skills of the family. Altogether, the empowerment program can be helpful for sick children and his/her parents to contract more efficiently with the disease and its complications to achieve a higher level of good care and good life (**Teymouri, Alhani, & Kazemnejad, (2011); Subandi, (2013) and Minooei, Ghazavi, Abdeyazdan, Gheissari, & Hemati, 2016**).

The CKD causes essential alteration in families and leads to severe complications, the family centered empowerment programs can diminish the hospital expense and the school absenteeism, and advance the physical and psychological health and accomplishments of children with CKD. Additionally, the family-centered empowerment programs are based on educational needs assessments, they may help nurses and physicians provide good health care services to children with CKD, leading to harmony and the endorsement of healthcare-related capability among these children and their families (**Minooei, et al., 2016**).

Mothers of children with CKD are facing complexity to manage their daily living activities. Understanding disease-related changes among the affected person in the family may help them to feel secure about the future. It also helps them to handle the situation within the family (**Shoghi, Shahbazi, & Seyedfatemi, 2019**). Nurses have an important role in increasing mothers' self-confidence and trust which in turn promotes family health and wellness. All family functions can be troubled as a result of worries and concern about their children health care needs, medical and educational services, cost of the disease, missing social opportunities, frequent absences from work and physical and psychological problems (**Ziegert, Fridlund, & Lidell, 2009**). With the use of various training methods, it helps to increase the knowledge of both children with CKD and their families regarding the disease and helps improve their adaptation to the disease, the use of communication and problem solving skills, and management of physical and psychological problem, and quality of life (**Sotoudeh, Pahlavanzadeh, & Alavi, (2019) and Masoudi, Alhani, Moghadassi, & Ghorbani, 2010**).

Importance of the Study

Children with CKD require more repeated care. Engagement highlights the significance of high-quality care and generates an optimistic approach toward life that can be accomplished, regardless of the constant disease. At the point, when moms has a greater understanding of their children medical problems and acquire a practical role in managing their health problems through teaching and participation, significant expenses of health care will be decreased. The empowerment in nursing includes an accentuation on common cooperation, information obtaining, indistinguishable association and shared dynamic in regards to medical issues and objectives (**Nygårdh, Wikby, Malm, & Ahlstrom, 2011**). Empowerment through including and teaching parents give them a feeling of intensity and responsibility in children's care, increase their fulfillment, and certainty that may prompt greater children's care. Educational interventions for the parents and family members of children with CKD also advance the quality of home care significantly (**KHORAMI, (2015)**). Teaching program involving family is one of the interference used for developing the information and attitude regarding the nature of disease and civilizing communication and problem solving skills. For that reason, our study was accomplished to investigate the consequence of empowering mothers caring for their children with CKD through engagement and education

II. Methodology

Aim of the study

The aim of this study was to evaluate effect of empowering mothers caring for their children with CKD through engagement and education. This aim can be achieved through:

1. Implementing family empowerment program through learning and involving mothers in providing care for their children.
2. Appraise the consequence of family engagement and education on mother's awareness and practice concerning home care of their children with CKD.

Hypothesis:

1. Mothers having children with CKD have greater family empowerment after implementation of family empowerment than before.

2. Engagement and Education have optimistic outcome on mothers' knowledge and performance concerning CKD management and home care.

III. Subjects and Methods

Research Design: A quasi-experimental study design (one group pre post test) was applied to fulfill the aim of the study.

Research settings: The study was conducted at kidney center in Aga Central Hospital, Dakahliah, Egypt.

Subjects:

A convenience sample consisted of 50 mothers and their children who are complaining from CKD from the above mentioned setting and satisfying the subsequent inclusion criteria: they are school age children aged from (6-12 years) and free from other chronic disease.

Data Collection Instruments:

Tool I: chronic kidney disease knowledge and home management questionnaire

This survey was designed by the researchers after reviewing related literature. This survey was designed to assess mothers' knowledge, practice and home management about CKD. The questionnaire was used pre/ post educational program; it was designed in the form of MCQ Arabic questions. Validity and reliability of the tool was done accordingly. The tool was included three parts:

Part 1: Mothers' and their children sociodemographic characteristics' including mothers age, educational level, mothers job, child age, gender, child educational level and family history of CKD.

Part 2: Mothers knowledge about CKD. it includes questions regarding definition, causes, signs and symptoms, complications, medical treatment, definition of hemodialysis, benefits, frequency per week, number of hours per session, risks of non attending dialysis sessions, precautions for fistula care, warning signs of fistula malfunctioning. This part has total marks (50).

Part 3: home care for children with CKD. It consists of questions about nutrition as following dietary regimen about kidney disease, types of food that should follow, risks if not follow kidney diet, types of food that must be restricted. Second; fluid therapy as using specific graduated cup for fluid intake & output daily, relation between fluid intake and output. Additionally, it was include questions about infection prevention, signs and symptoms of urinary tract infection, importance of measuring blood pressure & weight for kidney disease patient, exact time for measuring it. Total marks of this part were (28). The mother was considered that she has good knowledge if the total score was greater than 70%, score ranged between $50 \geq 70\%$ was average. While, score less than 50% was poor knowledge.

Tool II: Family Empowerment Scale

The scale was formerly developed by **Koren, DeChillo & Friesen (1992)** and adjusted by the "behavioral and developmental services: children's quality improvement, (2008)". It was five point likert scale and was summed up in this study to three points Likert scale for ease pertinence as follow: "Not at all true (1), somewhat true (2) and very true (3)". The scale was adapted, interpreted to Arabic and summed up. It was comprised of 34 objects inside three subscales including family, service system and community and political area. The family and services system compromised of 12 item in each; while, community political area constitute 10 statements. The instrument was examined for validity and reliability before study implementation.

A scoring framework was created; a score of each area is the aggregate of the item reactions. The higher score shows moderately greater empowerment in every subscale. To get a score for every subscale, total the item reactions and scored a similar way. The total score of "Family and service system" subscale was 36; "low empowerment" scored from 1 – 17; while, "moderate empowerment" score ranged from 18 to 26 and "higher empowerment" extended from 27 – 36. Additionally, community subscale total score was 30 as follow; "low empowerment" from 1 – 14; "moderate empowerment" scored 15 – 22 and the "higher empowerment" extended from 23 to 30.

Validity and Reliability

The survey instruments were adapted, interpreted, adjusted by the researcher and examined for validity by 5 specialized in the field of pediatric nursing. Additionally, the reliability was completed by Alpha Cronbach's test; the alpha reliability for instrument (I) was 0.712 and 0.750 for tool (II).

Pilot Study

It was done on 4 moms (10%) of the study sample to examine the simplicity, legitimacy and unwavering quality of the research instruments. The subjects engaged with the pilot study were removed from the entire sample and the essential changes were finished by the pilot study "as referenced before in tool II.

Ethical Considerations:

Agreement was acquired from the chiefs' directors of the hospital. Composed assent was acquired from the moms before their incorporation in the study after clarifying the main points and objectives of the study. Moms' cooperation was intentional and all data was coded and classification was thought of. The moms were educated that they reserve the privilege to pull back from the study anytime.

Work Field:

- Data was collected from the beginning of January to the end of May 2019.
- The educational guideline was implemented on 4 sessions; once every week & every session continued for 20- 30 minutes.
- In the first session, the researcher discussed the definition of CKD, causes, signs and symptoms, complications and medical treatment.
- Second session included definition of hemodialysis, benefits, frequency per week, number of hours per session, risks of non attending dialysis sessions, precautions for fistula care and warning signs of fistula malfunctioning.
- The third session included Knowledge regarding home care nutrition as following dietary regimen about kidney disease, types of food that should follow, risks if not follow kidney diet, types of food that should be not followed. Fluid therapy as using specific graduated cup for fluid intake & output daily relation between fluid intake and output. Infection prevention, importance of measuring blood pressure & weight for kidney disease patient, exact time for measuring it.
- In session four, the researcher make conclusion about the most important point. In addition, educational booklet was given to mothers. During all sessions, various media was utilized such as illustrative pictures, and recordings.

Statistical Analysis:

The gathered information was evaluated, organized and investigated by utilizing the SPSS bundle Version (23). The following tests and measurements are utilized as numbers and percentage, mean ± SD, Chi- square (χ^2) & (t) test. Statistical significance was accepted at P<0.05.

IV. Results

Table (1); Distribution of Mothers and their children According to Their Socio-demographic Characteristics

	No (50)	%
Mother's Age\ year		
> 30	9	18
30-40	33	66
< 40	8	16
Mean± SD	34.92±6.06	
Mothers' Job		
House wife	27	54
Technical	10	20
Academic	13	26
Child's Age\ year		
≥ 5	20	40
6 - 10	10	20
11 - 15	20	40
Mean age	8.34±4.38	
Child gender		
Male	23	46
Female	27	54
Child's Education		
Illiterate	11	22
Read & Write	17	34
Primary	8	16
Preparatory	14	28

Table (1) showed sociodemographic characteristics of the studied mothers and their children, it was observed that two thirds of mothers (66%) aged 30 to 40 year. & more than half of them (54%) were housewife. Additionally, more than half (54%) of studied children were females.

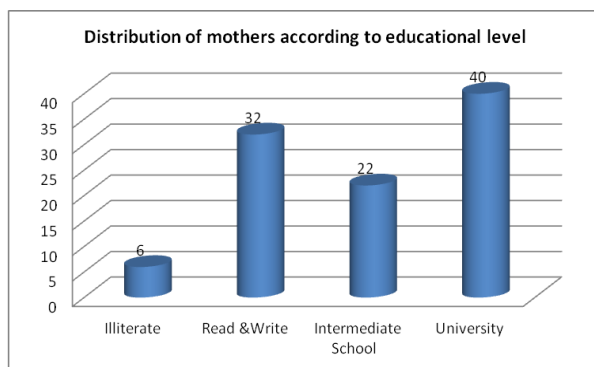


Figure (1): Distribution of mothers according to educational level

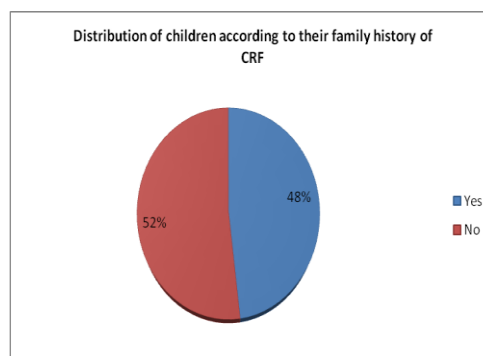


Figure (2): Distribution of children according to their family history of CRF

Figure (1), represented distribution of mothers according to their educational level; it was found that less than half of them (40%) had university education and approximately one third of them(32%) read and write.

Figure (2) shows that more than half (52%) of studied children had negative family history of chronic renal failure.

Table (2): Mean score of Mothers total knowledge regarding CKD Care & Home Management Pre and Post Intervention

Variable	Pre	Post	Test of significance	
	Mean± SD	Mean± SD	t	p - value
Total knowledge about disease process & dialysis	20.14± 6.02	33.98±6.92	-11.1	<0.001**
Home care measures nutrition	5.32± 1.30	9.58±1.83	-13.1	<0.001**
Fluid therapy & Infection prevention	2.40±0.85	2.72±0.45	-2.6	0.01**
Monitor blood pressure & weight frequently	2.28±1.08	3.48 ±.81	-6.04	<0.001**
Total Home care	53.82±.13.62	72.50±9.56	-8.05	<0.001**

*p < .001

There were an improvement in the mean score of mothers total knowledge and home management with statistically significant difference (P<0.001) in the post intervention phase compared to pre intervention phase as it was illustrated in table (2) mothers' knowledge regarding CKD care & home management.

Table (3); Mean score of family empowerment sub-scales and total level of family empowerment in the pre and post intervention phase

Variables	Pre test	Post test	t	p - value
	Mean± SD	Mean± SD		
Mean score of family empowerment sub-scales				
Family	35.32±5.24	46.54±6.56	-8.5	<0.001**
Services system	35.00±5.36	45.58±7.59	-7.8	<0.001**
Community	30.24±3.83	39.96±5.67	-9.2	<0.001**
Total level of family empowerment				
Low empowerment	90.66±5.23	99.25±0.50	-9.5	<0.001**
Moderate empowerment	105.31±2.72	0		
High empowerment	116.70±4.42	134.93±15.79		

*p < .001

Table (3) reveals mean score of family empowerment sub-scales and total level of family empowerment in the pre and post intervention phase. It was found that, there was highly statistical significant difference (P<0.001) pre and post intervention in family, services system & community subscales. Additionally, the level of family empowerment score was improved from 116.70±4.42 to 134.93±15.79 for higher empowerment with statistical significant difference.

Table (4); Relationship between total level of mothers' knowledge, home care about care of children with CKD and level of family empowerment

Variable	Pre			Post			Test of significance	
	Low empowerment	Moderate empowerment	High empowerment	Low empowerment	Moderate empowerment	High empowerment	t -test	p - value
Total knowledge level								
Good	1(100%)	0	0	2(8.7%)	0	21(91.3%)	-	
Average	1(100%)	0	0	2(20%)	0	8(80%)	-	
Poor	22(45.8%)	16(33.3%)	10(20.8%)	0	0	17(100%)	32.4	<0.001**
Total home care								
Good	17(70.8%)	6(25%)	1(4.2%)	9(19.6%)	10(21.7%)	27(58.7%)	22.9	<0.001**
Average	14(87.5%)	0	2(12.5%)	0	0	0	-	
Poor	8(80%)	1(10%)	1(10%)	0	2(50%)	2(50%)	7.4	0.002*

* $p < .05$ ** $p < .001$

Relationship between total level of mothers' knowledge, home care about care of children with CKD and level of family empowerment was represented in table (4). It was clear that more than half of mothers (58.7%) who had good level of home care had higher level of family empowerment in the post intervention with a statistical significant difference. Moreover, the majority of mothers (91.3%) who had good knowledge score in the post intervention phase also had higher level of family empowerment with a statistical significant difference.

Discussion

Children with CKD require more frequent hospital care. Empowerment is an essential element in preserving health and defeating illnesses. Be supposed to become a fundamental part of health care. **As a result**, this quasi-experimental study was conducted to appraise the effect of empowering mothers caring for their children with chronic kidney disease through engagement and education.

The results of the current study illustrated the demographic characteristics' of the studied mothers and their children and revealed that two thirds of mothers were in the age group from 30 to 40 years and more than half of children had negative family history of CKD. This results was supported by **Awaji, Al Thibani, Alsulami, Al Otaibi, & Moawad, (2019)** and **El-Karmalawy, Habib, Fadel, & Mahmoud, (2015)** they reported in their study that more than half of the studied mothers were in the same age group and 68% had no family history. Additionally, our results showed that more than half of children were females; this result was in contradiction with **Awaji, et al., (2019)** and in agreement with **El-Karmalawy, et al., (2015)**.

Regarding level of mothers knowledge about CKD and its management, the present study results confirmed that there was a statistical significant progress in the level of mothers' knowledge about disease management, dialysis process, home management including nutrition, blood pressure and weight monitoring after implementation of family centered empowerment intervention program. Similarly, **Minooei, et al., (2016)** and **Ghazavi, Minooei, Abdeyazdan, & Gheissari, (2014)** and **Mangione-Smith, Schiff, & Dougherty, (2011)**; they reported in their study that the family-cantered empowerment model resulted in an development of information and understanding of disease, decrease in the school absence and nonemergency admission, and generally increase in children's performance in school and their communities. Additionally, **Eidivandi, Rostami, Dashtbozorgi, & Haghhighizadeh, (2020)** reported in his study that the blended education resulted in a significant increase in parents' knowledge about CKD in the intervention group compared to the control group ($p < 0.05$). Also, **Khorami Markani, Khalkhali, Sakhaei, & Saheli, (2015)** and **Abu-Ouf, Abualhamyl, AlJahdali, & Kari, (2016)** showed that the family-centered care educational program improved the knowledge of the mothers of hemodialysis patients and improved the physical, mental status and quality of life of children with CKD. Moreover, family-centered care provided a basis for improving the physical and mental status of patients with CKD.

Concerning mothers' level of practice and home management about blood pressure and weight monitoring and infection prevention, the study demonstrated that the mothers' home management level was improved after implementation of empowerment intervention program with statistical significant difference. Our results was congruent with **Tang, Funnell, Brown, & Kurlander, (2010)** who conducted a study in the USA and showed that the empowerment of patients with type 2 diabetes throughout the weekly teaching had a enormous effect on weight control, diet, and blood glucose levels.

Diet compliance for children with CKD was considered the most challenges and difficult task in disease and home management. The study results showed that there was an improvement in the mean score of nutritional home management from 5.32 ± 1.30 in pre intervention compared to 9.58 ± 1.83 in the post

intervention phase. This result reflected the importance of dietary educational session provided for children and their mothers on improving diet compliance, home management and empowerment level. This result was supported by **Lee, (2018)** who studied "An empowerment program to improve self-management in patients with chronic kidney disease" and reported that dietary education given during group sessions and telephone counseling assisted the patients in satisfying personal goals and needs, and causes positive outcomes in dietary compliance.

Additionally, the study conducted by **Shojaeezadeh, Tol, Sharifirad, & Alhani, (2013)** revealed that using educational program based on empowerment model may perhaps advance the self-care behaviors among type 2 diabetic patients. Moreover, the results of a study in Taiwan illustrated that the use of family empowerment program had a positive effect on family functioning relative to the control of disease and reduction of symptoms of the disease in a child (**Yeh, Ma, Huang, Hsueh, & Chiang, 2016**). This result can be explained by the fact that well developed interventions program that include both children and their parents was considered the vital component of competent medical and nursing care for children with chronic condition.

It is evident that the children with CKD and undergoing hemodialysis to be engaged and involved in self-management if their self-care and self-efficacy is enhanced by empowerment programs. Empowerment of children and their care givers was considered a model of involvement utilized to help in decision making and self-care. The empowerment model includes self-management education, development of disease management and care, medication and nutrition adherence behaviors, problem solving, stress management, social support and motivation (**Moattari, Ebrahimi, Sharifi, & Rouzbeh, 2012**).

Our findings showed that family centered empowerment program was positively associated with improvement in the mean score of family empowerment in all subscales with statistical significant difference. The result was in harmony with **Minooei, et al., 2016** and **Ghazavi, Minooei, Abdeyazdan, & Gheissari, (2014)**; they reported in their study that family empowerment program positively reduce behavioral problem, improves children's function and advanced the quality of life of children (QOL) with CKD. The researchers point of view that empowerment program are based on complete awareness, understanding and involvement of children and their parents in all diseases related process and decision making process which in turn reduce family worries from disease complication and the future of their children and increase the level of disease acceptance and cooperation.

Numerous researches propose that the empowerment of care givers and children with CKD is connected with positive outcomes such as improvements in QOL. **Moattari, et al., 2012** and **Lee, (2018)** reported in their study that the critical target of an empowerment program is civilizing the capability to actively connect in everyday self-management through improvement of self-efficacy and its three categories of self-management which includes dietary compliance, problem-solving, and psychosocial well-being. They also reported that there is an improvement in patients' general self-management skills and expansion of problem-solving skills after implementation of empowerment program.

In conclusion, the study provides strong evidence that empowering mothers and children with CKD and undergoing hemodialysis through engagement and education was effective and causes positive improvement and development of mothers' knowledge and home management of the disease, increased disease acceptance and improved level of family empowerment.

V. Conclusion & Recommendations

Our study concluded that implementation of the family centered empowerment program were helpful for children with CKD and their parents. The program was effective in helping families to discover their insufficiency and sense capable enough to change their existing conditions. Consequently, the researchers recommended implementing family centered empowerment program for all children with other chronic diseases to increase disease acceptance and management, improves the quality of life and promote their healthcare-related function.

Conflict of interest

The researchers affirm that there is no conflict of interest.

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Samia A El Nagar, et. al. “Empowering Mothers Caring for their Children with Chronic Kidney Disease through Engagement and Education.” *IOSR Journal of Nursing and Health Science (IOSR-JNHS)*, 9(4), 2020, pp. 12-19.