Quality of Life for Children Suffering from Chronic Renal Problems An Assessment Study

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Abstract

Background : Chronic kidney disease (CKD) is a major health problem worldwide with increasing incidence and prevalence that is threatening to bring on the onset of a real 'epidemic' **Aim of the study:** was to assess the quality of life for children suffering from chronic renal problems. **Setting:** The study was conducted at both in and out patient departments/ pediatric hospital affiliated to Ain Shams University hospitals. **Sample size:** The study sample included all available children (154) suffering from confirmed chronic renal problems since 6 months, attending the previously mentioned setting over six months period and satisfying predetermined inclusion criteria (children aged 4-18years old, both genders) with exclusion of children suffering from other chronic illnesses either medical or mental). **Tools of data collection:** 1-A pre-designed questionnaire sheet that was developed by the researcher it consiste of 2 parts; Part I; it concerned with sociodemographic characteristics, Part II: it concerned with data related to studied sample knowledge parents and their children, 2-Quality of Life Inventory Scale (QOL): Quality of life inventory scale used to determine the level of quality of life for children suffering from chronic renal problems. **Results:** More than half of the studied sample had a negative level of physical domain of quality of life, less than half of them hadanegative level of psychological domain of QOL and more than one third of them had positive level of social domain of QOL and less than half of them had a positive level of communication domain of quality of life. **Conclusion**: Quality of life for children suffering from chronic kidney diseases was affected in all domains especially of physical and school domains. There are many factors related to characteristic of children, health condition, physical status, psychological status, social status, environmental condition and the current health services that affect the quality of life of children suffering from chronic kidney diseases. **Recommendation:** Emphasize the importance of early case finding, control and management and regular assessment of factors affecting the quality of life for chronic kidney diseases in children.

Key words: Quality of Life, Children, Nursing, Chronic Renal Problems.

Introduction

Independent of the initial cause, CKD is a clinical syndrome characterized by a gradual loss of kidney function over time. In particular, the Kidney Disease: Improving Global Outcomes (KDIGO) guidelines have defined CKD as abnormalities of kidney structure or function, present for more than 3 months, with implications to health. This definition has been formulated for the adult population, where CKD is a common and well-known health problem, but the KDIGO guidelines for definition and staging are not

fully applicable to the pediatric population **(KDIGO 2013)**. Worldwide, in pediatric population as aged 19 years and under, the annual rate is only 1-2new cases in every 100,000 children. The risk increases steadily with age. Moreover, boys are nearly twice as likely as girls to develop chronic renal disease **(Sharma, 2013).**

The total number of children attending Children's hospital affiliated to Ain Shams University at outpatient clinic, inpatient ward and hemodialysis unit was 71.000, 8000 and 75 respectively. As regards children suffering from chronic renal problems, it was foundthat from the above mentioned total number and setting that 1649 (2%), 338 (4%) and 75 children were suffering from chronic renal problems **(Children's hospital of Ain Shams University, 2012-2013).**

The focus of nursing care for pediatric chronic kidney disease patients emphasizes primary prevention, early detection and aggressive management. The nephrology nurse plays an integral role in a comprehensive health assessment, coordinating care, providing education, interventions and follow up **(Warady et al., 2007).**

Significance of the problem:

In pediatric population, the risk of chronic kidney disease increases steadily with age and the children's poor lifestyle that will affect the pediatric patient's function in the future. They will find themselves in a different social and economic reality. Therefore, it was important to carry out this study to shed light on quality of life for children suffering from chronic renal disease.

Aim of the Study

This study aimed to assess the quality of life for children suffering from chronic renal problems.

Research questions:

What is the quality of life for children suffering from chronic renal problem?

What are the factors that affect quality of life for children suffering from chronic renal problems?

Subjects and Methods:

Research design:

A descriptive design was used in the study.

Setting:

This study conducted in both in and out patient departments at pediatric hospital affiliated to Ain Shams University, Ain Shams University children hospital is one of the largest hospitals, in Egypt of pediatric and it serves a large number of children who are suffering from kidney disease.

Sampling technique:

Types: A purposive sample.

Sample size:

The total number of children attending Children's hospital affiliated to Ain Shams University at outpatient clinic, inpatient ward and hemodialysis unit was 71.000, 8000 and 75 respectively. As regards children suffering from chronic renal problems, it was foundthat from the above mentioned total number and setting that 1649 (2%), 338 (4%) and 75 children were suffering from chronic renal problems **(Children's hospital of Ain Shams University, 2012-2013).** This study

sampling size that include all available children suffering from confirmed chronic renal problems since at least previous 6 months which equals 154children and attending the previously mentioned setting over six months period satisfying predetermined inclusion criteria that children aged 4-18years old, both gender with exclusion of children suffering from chronic illness either medical or mental.

Tools of data collection:

1- A pre-designed questionnaire sheet that was developed by the researcher, after reviewing relevant literature. It wrote in a simple Arabic language to suit level of understanding of children to collect data include the following:

A- Characteristic of children (such as age, gender, rank, education, present health status, duration of illness, frequency of hospital admission)..etc.

B- Characteristic of accompanying parents (such as age, gender, marital status, level of education, occupation, residence).

C-Children's knowledge (and their mother when necessary) about chronic renal problems (such as definition, causes, clinical manifestation, treatment, care problems)…..etc.

2-Quality of Life Inventory Scale (QOL):

- Quality of life inventory scale used to determine the level of quality of life for children suffering from chronic renal problems. It composed of five items (physical, social, psychological, school functioning and general well being) **(Verni 2003).**

- A scoring system adapted for the gathered data in relation to children's knowledge about chronic renal problems and quality of their life.

- **Scoring system:**

According to answer, A correct response was scored 1 and incorrect zero for each area of knowledge, the scores of the items was summed-up and total divided by number of the items, giving a mean score for the item. Regarding the knowledge of the studied sample, 100 scores were allocated to all items of the questionnaire. Then the answers were checked with a key answer and accordingly the studied sample knowledge were categorized into two levels: satisfactory above 60% and unsatisfactory below than 60%.

- **Quality of life inventory scale (Varni, 2003):** Quality of life scale consists of five items in each report (physical, social, psychological, school functioning and general wellbeing) scores are ranged from (0-4)with zero representing never has problem , with (1)representing almost never has problem and , with (2) representing sometimes has problem and equal, with (3) representing often has a problem and equal, with(4)representing almost always has a problem and equal.

The items of the five scales (Physical functioning, Emotional functioning, Social functioning, School functioning and communication) on the peds QL Generic Scale, for ease of interpretability, items are reversed scored and linearly transformed to a 0-100 scale. So that higher scores indicate better QOL. To reverse score, transform the 0-4 scale to 0-100 as follows: 0 = 100, 1 = 75% ,2=50% , 3=25% and 4 = 0. The QOL for children with chronic kidney disease was classified according to their responses into high (≥75) moderate (50-75%) and low (≤50%).

Administrative design

An official permission to carry out the study was obtained the administrator of Ain Shams Children's Hospital through an

issued letter from the dean of the faculty of nursing/ Ain Shams University.

Ethical consideration:

Each study subject assured that all the gathered data used for research purpose only, they informed about the purpose and expected outcomes of the study and they assured that the study is harmless and their participation is voluntary and they have the right to withdraw from the study at any time and without given any reasons. They assured also that anonymity and confidentiality was guaranteed.

Pilot study

Pilot study was conducted involving 10% of the studied sample and their mothers to test the feasibility of the tools and the time consumed for filling in the questionnaire and also to test the language clarity of the tools.

Data obtained from the pilot study were analyzed, the part of question related to using the peritoneal dialysis was cancelled duo to there was no peritoneal dialysis for the children and accordingly the necessary pilot study. The completion of tools took about 45 minutes.

Field work:

The actual field work was carried out from the first week of July up to the end of December (2015). The researcher explained the purpose of the study to the parents and their children before starting the interview, where each parent and their children suffering from chronic kidney problems were interviewed individually. The researcher was available in the study setting three days/ week at morning shift (8am to 1pm from Sunday to Thursday).

Major of studied children wanted to explain every item to responded it and it took a lot of time for every case to end questionnaire.

V-Statistical analysis:

The gathered data were analyzed using the statistical package for social sciences, version 20.0 (SPSS Inc., Chicago, Illinois, USA). Quantitative data were expressed as mean± standard deviation (SD). Qualitative data were expressed as frequency and percentage.

The following tests were done:

- Chi-square (x^2) test of significance was used in order to compare proportions between two qualitative parameters.
- Spearman's rank correlation coefficient (RS) was used to assess the degree of association between two sets of variables if one or both of them was skewed.
- The confidence interval was set to 95% and the margin of error accepted was set to 5%. So, the p-value was considered significant as the following: Probability (P-value):

  – P-value $\leq$0.05 was considered significant.
  – P-value $\leq$0.001 was considered as highly significant.
  – P-value >0.05 was considered insignificant.

Result:

Table (1): showed that more than one third of the studied sample (39.6%) were in the age group between 4<10years, and the rest of them (31.8%) were in the age group between 14≤18years old. Near to two thirds (59.7%) of them were male, approximately one third of them (31.8%) were in secondary schools, near to half (46.7%) of

them were the first child in the family. More than three quarter (76.6%) of them were living in urban area.

Figure (1): illustrated that more than third of the studied sample (39.6%) were in age group between 4:<10 years.

Figure (2): illustrated that approximately one third of the studied sample (31.8%) were in secondary schools.

Figure (3): illustrated that near to half (46.7%) of the studied sample were the first child in the family.

Figure (4): illustrated that more than two quarter (76.6%) of the studied sample were living in urban area.

Figure (5): illustrated that more three quarter (77.9%) of the family size of studied sample were less than five members.

Table (2): As regard to the quality of life domain of the studied sample, it was clear that 70.2% and 66.8% of them were unsatisfied in relation to physical and school domain respectively, while 32.4% and 25.4% of the studied children were partial satisfied in relation to both social and communication domain.

Table (3): This table shows the relation between children demographic characteristics and total quality of life. The result found that there were statistically significant relation between total quality of life and age in years p-value <0.05; while gender, educational level, ranking and family size with p-value (>0.05) non-significant.

Table (1): Number and percentage distribution of the studied children according to their sociodemographic characteristics (n=154).

Items	No.	%
Age in years		
4:<10	61	39.6
10:<14	44	28.6
14:≤18	49	31.8
+ ±SD	10.6± 7.02	
Gender		
Male	92	59.7
Female	62	40.3
Educational level		
Not yet enrolled	12	7.8
Nursery school	15	9.7
Elementary phase	33	21.4
Secondary phase	49	31.8
Leak from education	45	29.3
Ranking		
First	72	46.7
Second	30	19.5
Third	18	11.7
4^{th} :- 7^{th}	32	20.8
7^{th}:-9^{th}	2	1.3
Residence		
Urban	118	76.6
Rural	36	23.4
Family size/member		
<5	120	77.9
5:<7	32	20.7
7:<9	2	1.3

Fig (1): Percentage distribution of the studied children according to their age (years).

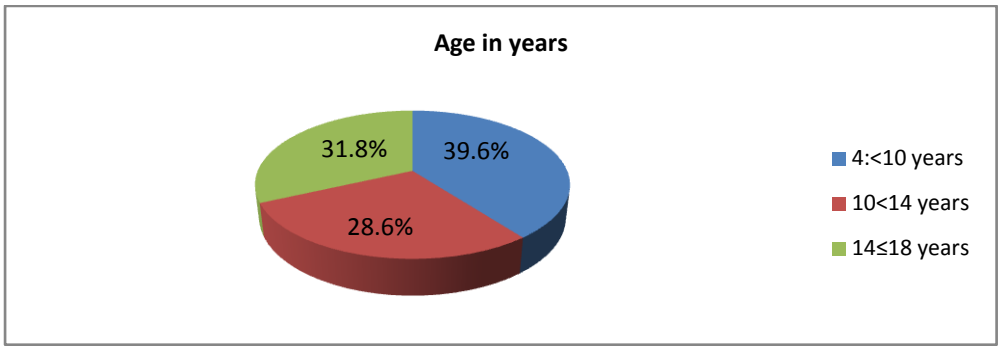

Fig. (2): Percentage distribution of the studied children according to their educational level.

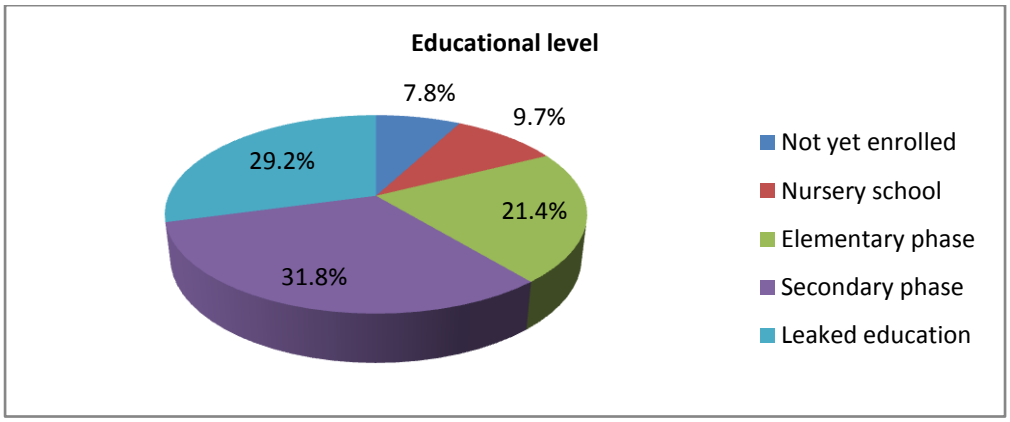

Fig. (3): Percentage distribution of the studied children according to their ranking.

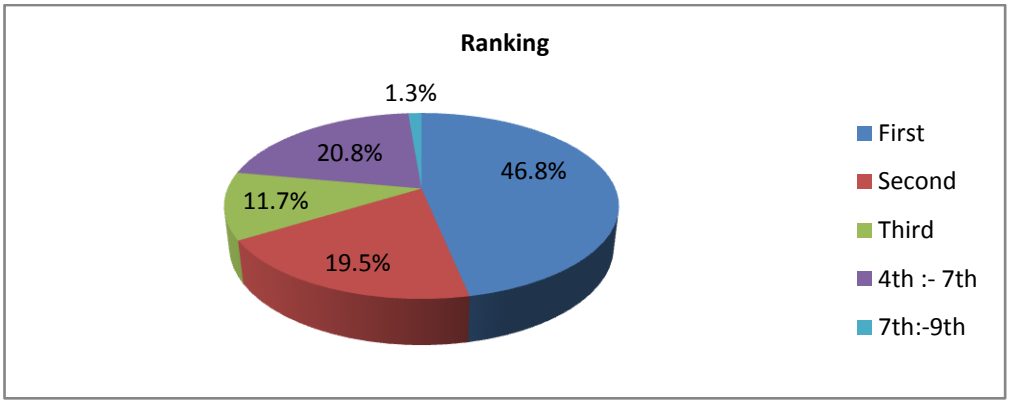

Fig. (4): Percentage distribution of the studied children according to their residence.

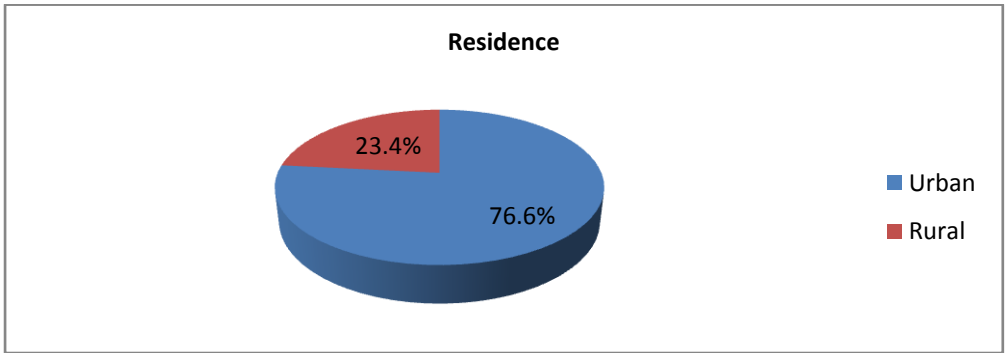

Fig. (5): Percentage distribution of the studied children according to their family size/member.

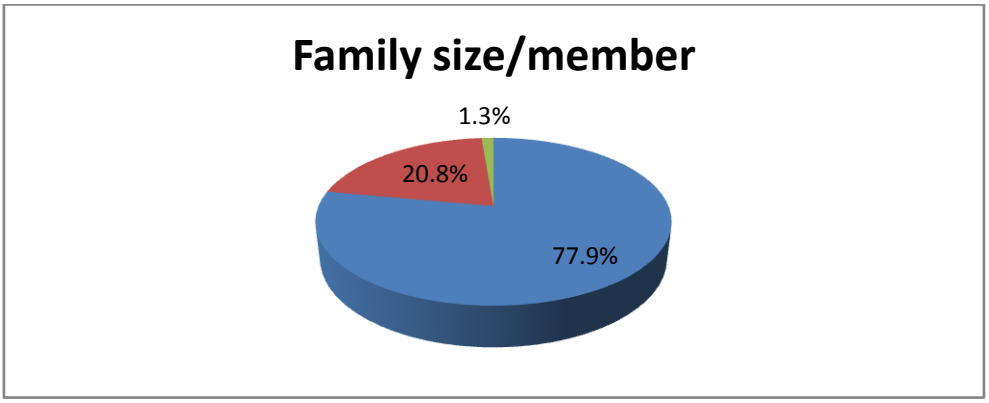

Table (2): Number and percentage distribution of the studied children according to their quality of life domains (n=154).

Domains	High QOL		Average QOL		Low QOL	
	No	%	No	%	No	%
1- Physical	13	8.4	33	21.4	108	70.2
2- Psychological	48	31.1	37	24	69	44
3- Social domain	61	39.6	39	25.4	54	35
4- School function	20	12.9	19	12	103	66.8
5- Communication	73	47.4	50	32.4	31	20.1
Total	44	28.6	36	23.4	74	48.1

Table (3): Relation between total quality of life and the demographic characteristics for child (n=154).

Children characteristics	Quality of Life						Chi-square test	
	Low QOL <50% (N=74)		Average QOL 50-75% (N=36)		High QOL >75% (N=44)		x2	p-value
Age in years								
4:<10	19	25.7	22	61.1	20	45.5		
10:<14	27	36.5	8	22.2	9	20.5	14.865	0.005*
14:≤18	28	37.8	6	16.7	15	34.1		
Gender								
Male	42	56.8	17	47.2	33	75.0	2.879	0.196
Female	32	43.2	19	52.8	11	25.0		
Educational level								
Not yet enrolled	5	6.8	2	5.6	5	11.4		
Nursery school	9	12.2	4	11.1	2	4.5		
Elementary phase	17	23.0	6	16.7	10	22.7	3.768	0.878
Secondary phase	22	29.7	12	33.3	15	34.1		
Leaked education	21	28.4	12	33.3	12	27.3		
Ranking								
First	35	47.3	13	36.1	24	54.5		
Second	14	18.9	7	19.4	9	20.5		
Third	9	12.2	5	13.9	4	9.1	5.437	0.721
4^{th} :- 7^{th}	15	20.3	11	30.6	6	13.6		
7^{th}:-9^{th}	1	1.4	0	0.0	1	2.3		
Family size/member								
<5	60	81.1	27	75.0	33	75.0		
5:<7	13	17.6	9	25.0	10	22.7	1.729	0.785
7:<9	1	1.4	0	0.0	1	2.3		

Discussion:

The CKDanditsconsequencesare a public health concern.The aimof CKD management is not onlythe improvement or substitution of kidney dysfunction, together with eliminating corresponding general health disorders, but also providing the patients suffering from the disease a suitable quality of life. CKD creates a difficult situation, not only for a CKD child but also for the family, which is very important for the child. The family creates the first, basic and sometimes the only social environment for the young growing patients **(Ajarmeh et al., 2012).**

The aim of the study was to assess the QOL among children suffering from CKD. Regarding to characteristics of the studied sample (table, 2), the result of the current study showed that the mean age was 10.6± 7.02 years. This finding was similar with the study by **Atta, (2012)** entitled (psychosocial troubles and quality of life in parents of children with chronic kidney diseases) which carried out at the Center of Children Nephrology and Transplantation in Cairo University, and found that more than half of the studied sample aged from 10 to less than 18 years old.The finding of the present study illustrated that more than half (59.7%) of the studied sample were males children (table, 2). This finding was supported by **Khalil, (2016)** found that more than half of the studied sample were male (57.3%) with male and female ratio 1.3:1.On the other hand, El-**Gamasy and Eldeeb, (2017)** study which entitled (Assessment of physical and psychosocial status of

children with ESRD under regular hemodialysis) in Tanta university/ Egypt and reported that near to two thirds of the studied children were females. One of the accepted explanation for this finding (2017) is the higher incidence of chronic glomerulonephritis in girls, secondary to neglected or inadequately treated acute post streptococcal glomerulonephritis, which is common in low socio-economic classes who spend more time indoors in poor housing conditions.

The present study illustrated that accompanying parent's age of children suffering from CKD of the studied sample (table, 3) more than half ranged between 25 to 45 with mean age was 38.7±11years. This finding was agreed with **Atta, (2012)** who studied psychosocial troubles and quality of life in parents of children with chronic kidney disease at the Center Of Pediatric Nephrology And Transplantation, Children's Hospital Cairo University, faculty of medicine, that Maternal age ranged from 20 to 50 years with mean age 34.1±6.3 years.

The present study showed that more than three quarters of the studied children live in home separate and Majority of them had tap water supply, majority were sewage disposed and more than half waste disposed remain outside the home (table 3) this is supported by **Krishnan et al., (2009)** who stated that the researcher believes that good environmental sanitation has positive effect on children nutritional status. This may due to the children are living in bad sanitation at greater risk of disease and more chance of nutritional disorder.

The present study illustrated that, near to quarter of the studied sample were the cause of chronic kidney diseases were heredity. This agreed with **Joachim et al., (2015)** entitled (psychosocial rehabilitation and satisfaction with life in adult with childhood – onset of end stage renal diseases) one third of them were the cause of chronic kidney diseases were hereditary nephropathsies.

The present study illustrated that, near to half of the studied sample treated by renal replacement therapy. This agreed with **Stephen et al., (2014)** entitled (long term survival of children with end stage renal diseases) who found that near to half of them started renal replacement therapy .

The present study illustrated that, half of the studied sample treated by had cardiovascular complication. This agreed with **Stephen et al., (2014)** entitled (long term survival of children with end stage renal diseases) who found that near to half of them had cardiovascular complication.

The present study illustrated that, the problems associated with hemodialysis of the studied sample the hypotension was the most side effect happened with dialysis and this finding is congruent with **Booth, et al, (2011)** entitled (Do Changes in Relative Blood Volume Monitoring Correlate to Hemodialysis- Associated Hypotension?) who found that, low blood pressure was the most commonside effect happened with hemodialysis.

In relation to total quality of life dimensions, the current study found near to half of the studied sample had low QOL, this finding is congruent with **Goldstein, (2016)** who studied(health-related quality of life in pediatric patient with ERSD) which found that children with CKD suffer continuously from stressful health problems that adversely affect all aspects of life, so they are in urgent need of physical, psychosocial, and financial support to enable their parents to adapt to these burden .

In relation to level of knowledge, the current study found that more than half of the studied sample had satisfactory

level of knowledge regard factors affecting quality of life, and this finding was agreed with **Amin, (2016)** who found more than half of them had satisfactory knowledge regard factors affecting quality of life for post kidney transplantation.

The present study showed in that there was a highly statistical significant relation between child rank between brothers and total knowledge ($p<0.01$), but there was no statistical significant difference between child gender and their total knowledge ($P>0.05$) the finding agreed with **Atta, (2012)** who found that there was no statistical significant relation between gender and total knowledge.

The finding of the present study represented that there was a highly statistical significant relation $P<0.001$ between total knowledge and total QOL, this finding agreed with **Mahmoud, (2016)** who found that there is highly statistical significant difference between total QOL of studied children and their total knowledge ($P>0.05$).

Conclusion:

Quality of life for children suffering from chronic kidney diseases was affected negatively in all domains especially of physical and school domains. There are many factors related to characteristics of the children, health condition, physical status, psychological status, social status, environmental condition and the current health services affected quality of life of children suffering from chronic kidney diseases. There was a highly statistical significant relation ($P<0.001$) between children total knowledge and total QOL.

Recommendations:

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

1. Regular assessment of factors affecting the quality of life for pediatric chronic kidney diseases at the pediatric nephrology and conservative nephrology clinics and the pediatric dialysis units.

2.Implementing programs to children with chronic kidney diseases and their parents for better quality of their life.

3. Emphasize the importance of early case finding and management through national screening and surveying programs targeting CKD in children.

4. Continuous educational training programs to children suffering from CKD and their mother to up-date their knowledge and practice regarding children's care. Encourage the importance of regular follow-up and investigation of children with CKD to ensure proper CKD control and early detection of complications.

Financial Support

No funding was received.

Conflict of interest:

No Yes

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