

⇒ Research Article



Assessment of Parental Awareness level of children with Chronic Kidney Disease in Ahvaz

Zainab Eydivandi¹, Fatemeh Jafari Naleshkenani¹, Rahim Pendar^{2*}¹Nursing Care Research Center in Chronic Diseases Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran²Research center for non-Communicable Diseases , Jahrom University of Medical Sciences, Jahrom, Iran**Abstract**

Background: Given the special care needs of children with Chronic Kidney Disease and the key role of the family in providing these health services, the level of parental knowledge and awareness about their child's disease status is essential. This study We aimed to determine the parental level awareness level of awareness of parents with children with Chronic Kidney Disease in Ahvaz.

Method: In this descriptive cross-sectional study, the census sampling method was used census. After completing demographic questionnaires and a researcher-made questionnaire, the level of parental knowledge and awareness was assessed in parents with children with Chronic Kidney Disease referred to Aboozar Hospital of Ahvaz.

Results: The study involved 42 children with Chronic Kidney Disease and their parents. The mean±SD age of the children was 9.85 ±1.22 and the mean±SD duration of illness was 11.18 ± 9.38 months. Knowledge and awareness of parents were rated as 3 subjects (7.14%), 38 (90.4%), and 1 (2.3%) parent with had poor Knowledge and awareness, 38 subjects (90.4%) as moderate, and 1 subject (2.3%) as good knowledge and awareness, respectively. There was no significant difference in the level of knowledge and awareness between any of the studied demographic variables studied ($P > 0.05$). Except for occupation that there was only one employee and the average level of awareness was lower than that of housewives. (I don't understand what you mean.)

Conclusion: The results of this study showed that parents of children with Chronic Kidney Disease did not have a sufficient level of knowledge and awareness about their child care. So it seems necessary to provide training programs for this group.

Keywords: Knowledge, Awareness Level, Chronic kidney disease, Child

***Correspondence to**Rahim Pendar,
Email: pendarr@yahoo.com

Received February 25, 2020, Accepted: June 4, 2021, Published Online: June 29, 2021

Background

Chronic kidney disease has been increasing in recent years. In the United States, its prevalence has increased six-fold in the last five years (1). Chronic kidney disease in children has an incidence of 18 per million individuals (2). In Iran, the number of children with chronic renal failure is 107 per million individuals (3). According to official reports in Iran, the annual incidence rate of chronic renal failure is 11 % (4). Chronic renal failure is defined as inappropriate and irreversible renal function (5). This ultimately leads to end-stage renal disease (ESRD) and requires one of the alternative kidney therapies including dialysis or transplantation (1). Chronic kidney disease is defined as kidney damage or glomerular filtration rate less than 60 ml/min per 1.73 m² of body surface area for three or more months (6). Despite the high cost of treatment, these patients suffer from depression, stress, and family and personal problems (7). Family support plays an important role in the acceptance of the disease by the patient and is also a strong factor in promoting and maintaining their quality of life (8). In children with

chronic illness, parents are the primary caregiver and thus have many challenges in coping with the child's complex problems and tasks (9).

In children with chronic kidney disease, consistent and intensive parental support is needed. Parent's mental, physical, and financial pressures can affect their ability to cope with their child's illness and the quality of care provided to their child (10). Parents of children with chronic kidney disease are often required to benefit from specific home interventions, including dialysis and patient-specific nutrition. Their family should constantly monitor the child's health, support appropriate health care, prepare for complications such as infection and other life-threatening complications, and attend frequent hospital visits. The parent's caregiving ability depends on their level of knowledge and awareness (11). Awareness of the child's illness reduces the parents' stress and fear (12). Parental anxiety not only occurs when the child is hospitalized but may continue until after the child is discharged, which may be related to the child's admission and the parents' lack of knowledge and their

inadequate information about the child's illness (13). Given the importance of family knowledge and awareness that improves the quality of life of patients and family members, we aimed to determine the level of knowledge and awareness of parents of children with chronic kidney disease and identify influencing factors.

Participants and Methods

This study was a descriptive cross-sectional study on all parents of children with chronic kidney disease aged 8-12 years referred to nephrology and medical clinics of Abouzar Hospital. Among the study population, parents of 42 children were selected based on the inclusion criteria. The sample size was calculated based on a previous study (14). The inclusion criteria were having least six months of childhood illness, age range of 8-12 years, having no underlying illness in the child, GFR (should be spelled out first) between 30-60 ml/min, being in stage three or four of chronic renal failure, no child hospitalization, and parents' willingness and ability to participate in the study.

After obtaining the Code of Ethics (IR.AJUMS.REC.1397.323) and introducing a letter from the Vice-Chancellor for Research Affairs of Ahvaz Jundishapur University of Medical Sciences to assess parental awareness, the demographic information questionnaire was given to the practitioners.

The demographic questionnaire included information on age, child GFR rate, stage of renal failure in the child, History of taking blood pressure medication education, and duration of the child's illness, as well as information on age, sex, number of children in the family, educational level, marital status, and occupational status of the parents.

A researcher-made questionnaire for assessing parental knowledge and awareness about chronic kidney disease and related care was compiled by the researcher, including items such as definition and cause, symptoms, complications, prognosis, treatment, and care. The knowledge and awareness questionnaire is a yes/no questionnaire consisting of 36 questions that are divided into three levels of poor (0-13), moderate (14-27) and good (28-36) based on the scores obtained. The mean scores of parents in each family were calculated as family awareness scores, and in families where only one parent completed the questionnaire, their awareness scores were considered as family awareness. The researcher-made questionnaire was designed and completed based on similar studies and literature review and under the supervision of professors. Content validity was used for measuring its validity. External and internal resources were used to prepare the questionnaire according to the subject under study. The questionnaire was distributed to the guidance and counseling professors and 10 nursing faculty members who were finally provided with corrective and supplementary feedback. It was re-examined and its scientific validity was confirmed. The test-retest method

(10 days interval) was used to assess the reliability of the questionnaire. 20 participants who matched the sample characteristics of the study were randomly selected and completed the questionnaire within 10 days. The correlation coefficient for the knowledge questionnaire was $r=0.88$, indicating good reliability. Content validity was used to assess the validity of the questionnaire and 10 experts were asked to submit their qualitative comments after the questionnaire was completed. Cronback's alpha was 0.96 indicating desirable internal consistency.

Results

The study involved parents of 42 children. Their mean \pm SD age was 9.85 ± 1.22 and the mean duration of disease was 11.18 ± 9.38 .

As shown in Table 1, 71.42% of the children were boys and most were 9 years old (35.7%). Most were primary school children (97.06%), the frequency of children who took antihypertensive medication was higher (97.06%). The highest percentage of children with the disease was 6-12 months (80.33%). The highest GFR was less than 60 ml/min and most children were in the third stage of renal failure (78.57%). Most families had three children (43.8%). Most fathers were 36-45 years old (54.50%) most of the mothers were 36-45 years old (57%). All parents lived together (100%). 18 (42.85%) parents had elementary school education. In terms of economic status, most families had an income of 10-20 million IR Rials (69.04%) and most of the mothers were housewives (97.06%) (Table 1).

Moreover, 7.14%, 90.47%, and 2.30% of the parents had low, moderate, and good levels of awareness, respectively (Table 2).

Discussion

In the current study, we examined the level of awareness of parents of children with chronic kidney disease. We found that the parents' knowledge level about their child's illness was mostly moderate and poor (97.7%). Therefore, to better manage the child's illness, families need to be able to make effective and purposeful decisions that are appropriate for and consistent with their lifestyle. Moreover, they should consider any physical, psychological, social, and individual factors. Because of the chronic nature of chronic kidney disease which may cause a serious family problem and has physical, economic, social and emotional consequences, family education can be effective in achieving health goals and reducing problems. On the other hand, the high prevalence of chronic kidney disease indicates the need to control this chronic disease to improve their quality of life, promote physical and mental health, and reduce its adverse effects in children and reduce the heavy financial burden on the health care system, and support the affected children. Patients with chronic kidney disease and their families

appear to have suboptimal health behaviors in our study, unlike Young's study (15).

In a study by Tong and et al a review was conducted and they found that parents with Chronic Kidney Disease need to provide high-level care, problem-solving, information-seeking, and financial and practical skills in addition to their normal parenting role(16).

In the Wai-Tong Chien and et al study was shown

Table 1. Demographic information of the participants

		Frequency (%)
Child sex	Boy	30 (71.42)
	Girl	12 (28.50)
Child age (year)	8	11 (26.60)
	9	15 (35.70)
	10	10 (23.90)
	11	3 (7.10)
Child education	2	3 (7.10)
	Elementary	41(97.06)
	Secondary	1 (2.94)
Antihypertensive medication	Yes	41 (97.06)
	No	1 (2.94)
Duration of the child's illness	6-12 (Month)	35 (80.33)
	13-19 (Month)	2 (4.77)
	20-26 (Month)	5 (11.90)
GFR (Per minute)	Less than 60 ml(stage 3)	33 (78.57)
	Less than 30 ml (stage 4)	9 (21.43)
Number of children in families	one	1 (2.40)
	Two	13 (31)
	Three	18 (43.8)
	Four	8 (19)
	five	2 (4.8)
Age of parents	Father	5 (12)
	Mother	14 (33.4)
	Father	23 (54.5)
	Mother	24 (57)
Marital status of parents	Father	14 (33.50)
	Mother	4 (9.60)
	Common life	42 (100)
	Divorce	-
Parental education	Deceased	-
	illiterate	6 (14.28)
	elementary	18 (42.85)
	secondary	14 (33.33)
Economic status of the family	thirty school	2 (4.76)
	University	2 (4.76)
	10-20 (rials) Million	29 (69.04)
Parental Employment Status	20-30 (rials) Million	13 (30.95)
	Housewife	41 (97.06)
	Employee	1 (2.94)

Table 2. Frequency and percentage of parental awareness level

Level of awareness	Frequency	Percent
Poor (0-13)	3	7.14
Moderate (14-27)	38	90.47
Good (28-36)	1	2.30

children with chronic kidney disease need care in addition to regular care, which can lead to improved outcomes for their children (17).

However, according to Plantinga et al review study, there is little information that shows improved patient outcomes with more parental awareness. The importance of parental awareness of Chronic Kidney Disease in the early stages of the disease for drug regimens cannot be underestimated(18).

Conclusion

In this study, the knowledge and awareness of parents with children with chronic kidney disease were insufficient. Therefore, it is recommended that parents with children with chronic kidney disease be educated. Investigating the causes of these deficiencies will require further studies to properly plan parental education.

It should be noted that the above article has been extracted from the master's thesis entitled "The Effect of Blended Instruction on Improving Knowledge and Practice of Parents of Children with Chronic Kidney Disease in the Therapeutic Care of Children.

Authors' Contribution

Study concept and design: A.Z; analysis and interpretation of data: P.R ; drafting of the manuscript: J.F; critical revision of the manuscript for important intellectual content: A.Z , P.R , J.F; statistical analysis: P.R

Conflict of Interests

In writing this paper, there is no conflict of interest among the authors of the paper, nor the research supporting organization,namely Ahvaz Jundishapur University of Medical Sciences.

Ethical Approval

IR.AJUMS.REC.1397.323

Funding/Support

This study was supported by ahvaz jundishapuo of medical science.

References

1. Ghods AJ, Savaj S. Iranian model of paid and regulated living-unrelated kidney donation. Clin J Am Soc Nephrol. 2006;1(6):1136-45. doi: 10.2215/cjn.00700206.
2. Rockville, MD, EMMES, 2007. <https://web.emmes.com/study/ped/announce.Htm>. Accessed 2019.
3. Sharifian M, Karimi A, Rafiee Tabatabaei S, Anvaripour N.

- Microbial sensitivity pattern in urinary tract infections in children: a single center experience of 1,177 urine cultures. *Jpn J Infect Dis.* 2006;59(6):380-2.
4. Lesan-Pezshki M, Matini M, Tagadosi M. Assessment of quality of dialysis in Kashan. *Feyz.* 2001;17(2):82-7. [Persian].
 5. Nasabeh Z, Hazrati M. *Medical Surgical Nursing.* Tehran: Salemi-Jame Negar; 2008. [Persian].
 6. Levey AS, Coresh J. Chronic kidney disease. *Lancet.* 2012;379(9811):165-80. doi: 10.1016/s0140-6736(11)60178-5.
 7. Monfared A, Khosravi K. The assessment of ESRD causes in hemodialysis patient in Guilan. *Guilan Univ Med Sci J.* 2003;12(46):76-82. [Persian].
 8. Hockenberry M, Wilson D, Rodgers C. *Wong's Essentials of Pediatric Nursing.* Elsevier Health Sciences; 2016.
 9. Hovey JK. Fathers parenting chronically ill children: concerns and coping strategies. *Issues Compr Pediatr Nurs.* 2005;28(2):83-95. doi: 10.1080/01460860590950863.
 10. Plantinga LC, Tuot DS, Powe NR. Awareness of chronic kidney disease among patients and providers. *Adv Chronic Kidney Dis.* 2010;17(3):225-36. doi: 10.1053/j.ackd.2010.03.002.
 11. Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child Care Health Dev.* 2010;36(4):549-57. doi: 10.1111/j.1365-2214.2010.01067.x.
 12. Sadri GH, Gholshiri P, Farajzadegan Z, Sahafi M, Najibi A. Is there any relationship between women family functioning and health self-care? *Journal of Isfahan Medicine Faculty.* 2010;29(166):1-10. [Persian].
 13. Voorde RG. Management of CKD. In: Avner ED, Harmon WE, Niaudet P, eds. *Pediatric Nephrology.* 6th ed. Berlin, Heidelberg: Lippincott Williams & Wilkins; 2009. p. 1661-16922.
 14. Sadeghzadeh V, Raeissi P. Evaluation of an integrated group education program on quality of life, anxiety and depression for family members of patients living with heart failure. *J Nurs Educ.* 2017;6(2):63-70. [Persian].
 15. Young EW, Mauger EA, Jiang KH, Port FK, Wolfe RA. Socioeconomic status and end-stage renal disease in the United States. *Kidney Int.* 1994;45(3):907-11. doi: 10.1038/ki.1994.120.
 16. Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics.* 2008;121(2):349-60. doi: 10.1542/peds.2006-3470.
 17. Chien WT, Chiu YL, Lam LW, Ip WY. Effects of a needs-based education programme for family carers with a relative in an intensive care unit: a quasi-experimental study. *Int J Nurs Stud.* 2006;43(1):39-50. doi: 10.1016/j.ijnurstu.2005.01.006.
 18. Plantinga LC, Tuot DS, Powe NR. Awareness of chronic kidney disease among patients and providers. *Adv Chronic Kidney Dis.* 2010;17(3):225-36. doi: 10.1053/j.ackd.2010.03.002.