

⇒ Research Article



Assessment of Parental Performance of Children with Chronic Kidney Disease in Ahvaz

Zainab Eydivandi¹ , Fatemeh Jafari Naleshkenani¹, Rahim Pendar^{2*} ¹MSc Student of Nursing, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran²Research Center for Social Determinants of Health, Jahrom University of Medical Sciences, Jahrom, Iran**Abstract**

Background: Children with chronic kidney disease (CKD) experience many complications such as anemia, growth failure, stress and emotional problems. The responsibility for providing these children with proper health care is their family. The way parents of a child with CKD act is very important in the care of their child. We aimed to evaluate the level of performance of parents with children with CKD in Ahvaz.

Method: In this descriptive cross-sectional study, census method was used for sampling. After completing the demographic questionnaires, the Family Assessment Device questionnaire (in general performance dimensions, communication, problem solving, role, emotional responsiveness, emotional involvement, behavior control) was used to assess parental performance of these children.

Results: The study involved 42 parents of children with CKD. 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. The results showed that the scores related to general performance ($P=0.001$), performance communication ($P=0.001$), problem-solving function ($P=0.024$), performance role ($P=0.038$), emotional performance response ($P=0.001$), emotional performance involvement ($P=0.001$), performance behavior control ($P=0.001$) of the study population was significantly higher than the permissible value set by the questionnaire providers, indicating worse performance.

Conclusion: The results showed that parents of children with CKD did not have a sufficient level of performance in caring for their children. Therefore, it seems necessary to provide training programs for this group.

Keywords: Functional level, Chronic kidney disease, Child

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

Received February 25, 2020, Accepted: December 9, 2021, Published Online: December 29, 2021

Background

Chronic kidney disease (CKD) is one of the major public health problems worldwide (1). Chronic kidney failure means inadequate kidney function below 15% of the normal function. Without alternative treatment many people will not be able to survive and require hemodialysis or kidney transplantation. CKD is defined as kidney damage or glomerular filtration rate less than 60 mL/min/1.73 m² of body surface area for 3 months or more (2). Despite many efforts to prevent serious kidney disease, the number of these patients is increasing in the country (1). Statistically, 5-10% of children in the US suffer from chronic kidney failure (3). In Iran, 5.37% of children with CKD have high systolic or diastolic blood pressure, 74% have anemia, 70% have bone disease, and 63% experience growth failure (1). International statistics show the growing trend of the disease in children and Iran. However, the survival and lifestyle of these children require the use of special care programs and diets. Appropriate therapies are required and, if absent, children and their families could be subjected to constant and chronic stress and, as a result, experience many

emotional and behavioral problems (4). The family, as the most important pillar of the society, is responsible for providing the patient with appropriate health care. Lack of family support can hinder the process of treating the sick child (5). While caring for a patient, his or her family needs a proper understanding of the disease, and such an approach will promote family health and well-being (6).

Children with CKD require specific dietary and lifestyle guidelines and frequent monitoring by a medical team (7). Illness and hospitalization of the child alter the daily life process as well as the role of the parents (8). Long-term illness, myriad complications, unexpected costs, and sometimes the loss of a parent's job put heavy burdens on the parents of these children (9-11).

Although dialysis is very life-saving, it is considered a heavy burden for the patient and the family. Previous studies have reported negative parental experiences in caring for a child with CKD. Studies have shown that the parents of these children may have higher levels of anxiety. They also have higher rates of depression (12), lower quality of life and health (13), have less time to spend with healthy siblings (14, 15), and also experience

more marital stress (16). Most of all, the financial burden of treatment can cause many problems (17).

Due to the complexity of the care needed for these children, their parents have the responsibility of providing health care in addition to their usual responsibilities. The quality of care provided by parents has important consequences for their children (18). Because of the central role of parents in the care of children with CKD, parental functioning is of paramount importance (19). Lack of proper parental functioning can in turn have a devastating effect on the child's personal development and medical care (20). For children with CKD, the best health outcome relates to how their parents function, so this study examined the functional status of these parents.

Materials and Methods

This study was a descriptive cross-sectional study that was performed to evaluate the level of performance of parents with children with chronic renal failure in Aboozar Medical Center in Ahvaz, Iran. The study population consisted of parents with children aged 8-12 years with chronic renal failure who referred to nephrology clinics and the clinic of Abu Dhar hospital. The sampling method was census and among the study population, parents of 42 children with chronic renal failure were selected based on the inclusion criteria. The sample size calculation was based on a previous study (21). Inclusion criteria were as follows: at least six months of childhood illness in the age range of 8-12 years, no underlying illness in the child, glomerular filtration rate (GFR) between 30-60 mL/min, being in the third and fourth stages of chronic renal failure, no hospital admission, and parents' willingness and ability to participate in the study. After obtaining the Code of Ethics (IR.AJUMS.REC.1397.323) and showing a letter from the Research Chancellery of Ahvaz Jundishapur University of Medical Sciences, demographic information questionnaire and the Family Assessment Device (FAD) were used to measure parental performance. The demographic questionnaire included information on age, education, child GFR rate, stage of renal failure, history of taking blood pressure medication, and duration of the child's illness, as well as information on age, gender, educational level, marital status, number of children in the family and occupational status of the parents. The Persian version of the FAD or McMaster standard questionnaire was used to assess family performance. This tool measures self-reported perceptions of family members. The questionnaire has 60 questions in seven dimensions including general performance (13 questions), problem-solving (6 questions), communication (7 questions), roles (9 questions), emotional interplay (8 questions), behavior control (10 questions), and emotional response (7 questions). The items are scored based on a four-point Likert's scale (Completely agree=1, agree=2, disagree=3, and strongly disagree=4). Reliability of the

Persian version of the FAD was confirmed by Yousefi and colleagues. The Cronbach's alpha for all scales was 94% in 2006. The validity of the instrument was confirmed by factor analysis and classifier method for 60 items and the seven dimensions to be 83% and 82%, respectively (22). The reference values offered by the questionnaire's creators are shown in Table 1 (23).

The mean scores of parents in each family were calculated as family performance scores, and in families where only one parent completed the questionnaire, their performance scores were considered as family performance. SPSS software, version 22, was used for data analysis. Descriptive statistics (mean, standard deviation and frequency distribution tables) were used to describe the characteristics of the research variables.

Results

Forty-two children participated in this study with a mean \pm SD age of 9.85 ± 1.22 years and a mean \pm SD duration of disease of 11.18 ± 9.38 months.

As shown in Table 2, most of the children with CKD were boys (71.42%), and most of the children were nine years old (35.70%). Most children were in primary school children (97.06%), and the frequency of children who took antihypertensive medication was higher (97.06%). Most children had the disease for 6-12 months (80.33%). The highest percentage of GFR was less than 60 ml/per minute or the child was in the third stage of renal failure (78.57%). Families with three children had the highest percentage (43.80%). Most fathers were 36-45 years old (54.50%) and most mothers were 36-45 years old (57%). All the parents lived together (100%). The highest percentage of parental education was elementary school (42.85%). In terms of economic status, the income of most families was 10-20 million Rials (69.04%) and most of the parents were housewives (97.06%).

As shown in Table 1, the mean scores of the study questionnaires were compared with the allowable

Table 1. Performance Dimension Scores and Comparison With the Reference Value

| | Suitable Level Lower Than the Cut-Off | Mean \pm Standard Deviation | P Value ^a |
|--------------------------------|---------------------------------------|-------------------------------|----------------------|
| General performance | 2 | 2.87 \pm 0.45 | 0.001 |
| Performance Relationship | 2.2 | 2.83 \pm 0.65 | 0.001 |
| Problem-solving function | 2.2 | 3.44 \pm 0.76 | 0.001 |
| Role of performance | 2.3 | 2.41 \pm 0.39 | 0.024 |
| Emotional performance response | 2.2 | 2.71 \pm 0.84 | 0.035 |
| Emotional conflict of function | 2.1 | 2.49 \pm 0.37 | 0.001 |
| Performance behavior control | 1.92 | 2.57 \pm 0.34 | 0.001 |

^a Sample t test.

Table 2. Demographic Information of the Children

| | | No. (%) | |
|--------------------------------|---------------------------|------------|------------|
| Gender | Boy | 30 (71.42) | |
| | Girl | 12 (28.50) | |
| Age (y) | 8 | 11 (26.60) | |
| | 9 | 15 (35.70) | |
| | 10 | 10 (23.90) | |
| | 11 | 3 (7.10) | |
| | 2 | 3 (7.10) | |
| Education | Elementary | 41 (97.06) | |
| | Secondary | 1 (2.94) | |
| Antihypertensive medication | Yes | 41 (97.06) | |
| | No | 1 (2.94) | |
| Duration of illness (mon) | 6-12 | 35 (80.33) | |
| | 13-19 | 2 (4.77) | |
| | 20-26 | 5 (11.90) | |
| GFR (min) | 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 (43.80) | |
| | Four | 8 (19) | |
| | Five | 2 (4.80) | |
| Age of parents (y) | 26-35 | Father | 5 (12) |
| | | Mother | 14 (33.40) |
| | 36-45 | Father | 23 (54.50) |
| | | Mother | 24 (57) |
| | 46-55 | Father | 14 (33.50) |
| | | Mother | 4 (9.60) |
| Marital status of parents | Married | 42 (100) | |
| | Divorced | - | |
| | Deceased | - | |
| Parental education | Illiterate | 6 (14.28) | |
| | Elementary | 18 (42.85) | |
| | Secondary | 14 (33.33) | |
| | High school | 2 (4.76) | |
| | University | 2 (4.76) | |
| Economic status of the family | 10-20 (Million Rials) | 29 (69.04) | |
| | 20-30 (Million Rials) | 13 (30.95) | |
| Parental Employment Status | Housewife | 41 (97.06) | |
| | Employed | 1 (2.94) | |

thresholds provided by the criteria provided in the FAD. The results using simple t test showed that scores of general performance ($P=0.001$), performance relationship ($P=0.001$), performance problem-solving ($P=0.024$), performance role ($P=0.038$), emotional responsiveness ($P=0.001$), emotional performance involvement ($P=0.001$) and performance behavior control ($P=0.001$) were significantly higher in the study population (higher

scores were considered to be a worse situation).

Discussion

In order to successfully manage a child's illness, families need to be able to effectively target and make decisions that are appropriate to their life style and include many physical, mental, social, and individual factors. Because of the chronic nature of CKD which has physical, economic,

social, and emotional consequences, family education can be used to achieve health goals and reduce problems.

Children with chronic renal failure and their families seem to change favorable health behaviors. Our study revealed the poor performance level of the parents of these children. Another study showed that parents of children with CKD need high levels of care, problem-solving skills, information seeking, and financial and practical skills at a time when they have the capacity to cope with fatigue (24). In our study the results showed that parents did not at high levels of ability, so training programs for parents to raise awareness were necessary. A study by Tsai et al showed that parents of children who were dialyzed had increased rates of depression and poorer quality of life compared to parents of healthy children. Since stress, anxiety, and depression are used to measure coping, parents with increased levels of stress, anxiety, and depression may have more difficulty adjusting to their child with kidney failure (12). Emphasizing on family involvement in patient care, this is still rarely planned and implemented as a formal process in client education. On the other hand, although the efficacy of combination education has been confirmed in patients with chronic illness (25), so far no study has been performed on the impact of this effectiveness on families of children with CKD. Also, due to the chronic nature of CKD, which impairs family foundations and has physical, economic, social, and emotional consequences (26), family education can be effective in achieving health goals and reducing problems (27). Socioeconomic status can be a factor affecting how families adjust to having a child with kidney failure. Researchers found that low socioeconomic status was associated with decreased adherence to treatment (28). Also, low socioeconomic status was associated with increased levels of anxiety and depression in the parents. These results support the idea that families with low socioeconomic status may have more difficulty adjusting with a child with kidney failure. The mechanism of this relationship is unknown, but may be related to the increased level of general stress associated with low socioeconomic status (16).

The overall burden of caring for a child with CKD is stressful and is characterized by themes such as uncertainty, social isolation, and increased care, alertness, and supervision. MacDonald interviewed parents who had children with peritoneal dialysis (PD), and found that parents are often concerned about the likelihood of illness or death and are very vigilant in monitoring child health. The parents also regularly examined their children at night, describing fatigue and despair. In addition, mothers found that friends and family members visited less frequently, leading to social isolation (29). Similar to our study, another study showed that patients' families had low self-efficacy and low performance in accompanying their patients because of their lack of active treatment, and

therefore did not have a good quality of life. Therefore, providing education and facilitating family participation in patient treatment can improve family functioning and self-efficacy (30).

Conclusion

The results of this study showed that parents of children with CKD did not perform adequately in caring for their children. Therefore, it seems necessary to provide training programs for this group. Investigating the causes of these deficiencies will require further studies to properly plan for parental education.

Acknowledgment

This study has been extracted from the master's thesis entitled "The Effect of Blended Instruction on Improving Knowledge and Practice of Parents of Children with CKD in the Therapeutic Care of Children".

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

This study was approved by Ahvaz Jundishapur University of Medical Sciences (Code of Ethics: IR.AJUMS.REC.1397.323)

Funding/Support

This study was supported by Ahvaz Jundishapur University of Medical Sciences.

References

1. Coresh J, Selvin E, Stevens LA, Manzi J, Kusek JW, Eggers P, et al. Prevalence of chronic kidney disease in the United States. *JAMA*. 2007;298(17):2038-47. doi: [10.1001/jama.298.17.2038](https://doi.org/10.1001/jama.298.17.2038).
2. Levey AS, Coresh J. Chronic kidney disease. *Lancet*. 2012;379(9811):165-80. doi: [10.1016/s0140-6736\(11\)60178-5](https://doi.org/10.1016/s0140-6736(11)60178-5).
3. Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Epidemiology of chronic kidney disease in children. *Pediatr Nephrol*. 2012;27(3):363-73. doi: [10.1007/s00467-011-1939-1](https://doi.org/10.1007/s00467-011-1939-1).
4. Sharifian M, Karimi A, Tabatabaei SR, 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.
5. Alonso EM, Neighbors K, Barton FB, McDiarmid SV, Dunn SP, Mazariegos GV, et al. Health-related quality of life and family function following pediatric liver transplantation. *Liver Transpl*. 2008;14(4):460-8. doi: [10.1002/lt.21352](https://doi.org/10.1002/lt.21352).
6. Hockenberry MJ, Wilson D, Rodgers CC. *Wong's Essentials of Pediatric Nursing*. Elsevier Health Sciences; 2016.
7. National Kidney Foundation, Kidney Disease Outcomes Quality Initiative. Clinical practice guidelines for nutrition in chronic renal failure. II. Pediatric guidelines. *Am J Kidney Dis*. 2000;35(6 Suppl 2):S105-S36. doi: [10.1053/ajkd.2000.v35.aajkd035105](https://doi.org/10.1053/ajkd.2000.v35.aajkd035105).
8. Bsiri-Moghaddam K, Basiri-Moghaddam M, Sadeghmoghaddam L, Ahmadi F. The concept of hospitalization of children from the view point of parents and children. *Iran J Pediatr*. 2011;21(2):201-8.
9. Mirlashari J, Rasoli M. *Nursing of Children, Sick Child*. 5th ed. Vol 2. Tehran: Andisheh Rafi Publications; 2017. p. 11-35.

- [Persian].
10. Bignall ON 2nd, Goldstein SL. Childhood CKD affects the entire family. *Am J Kidney Dis.* 2015;65(3):367-8. doi: [10.1053/j.ajkd.2014.11.013](https://doi.org/10.1053/j.ajkd.2014.11.013).
 11. Abbasi A, Ashraf-Ebrahimi N, Asayesh H, Shariati A, Rahmani H, Mollaei E. Relationship between caregivers burden and counter skills in hemodialysis patient. *J Urmia Nurs Midwifery Fac.* 2012;10(4):532-9. [Persian].
 12. Tsai TC, Liu SI, Tsai JD, Chou LH. Psychosocial effects on caregivers for children on chronic peritoneal dialysis. *Kidney Int.* 2006;70(11):1983-7. doi: [10.1038/sj.ki.5001811](https://doi.org/10.1038/sj.ki.5001811).
 13. Wiedebusch S, Konrad M, Foppe H, Reichwald-Klugger E, Schaefer F, Schreiber V, et al. Health-related quality of life, psychosocial strains, and coping in parents of children with chronic renal failure. *Pediatr Nephrol.* 2010;25(8):1477-85. doi: [10.1007/s00467-010-1540-z](https://doi.org/10.1007/s00467-010-1540-z).
 14. Cimete G. Stress factors and coping strategies of parents with children treated by hemodialysis: a qualitative study. *J Pediatr Nurs.* 2002;17(4):297-306. doi: [10.1053/j.pdn.2002.126712](https://doi.org/10.1053/j.pdn.2002.126712).
 15. 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](https://doi.org/10.1111/j.1365-2214.2010.01067.x).
 16. Fielding D, Brownbridge G. Factors related to psychosocial adjustment in children with end-stage renal failure. *Pediatr Nephrol.* 1999;13(9):766-70. doi: [10.1007/s004670050695](https://doi.org/10.1007/s004670050695).
 17. Laakkonen H, Taskinen S, Rönholm K, Holmberg C, Sandberg S. Parent-child and spousal relationships in families with a young child with end-stage renal disease. *Pediatr Nephrol.* 2014;29(2):289-95. doi: [10.1007/s00467-013-2618-1](https://doi.org/10.1007/s00467-013-2618-1).
 18. Gerson AC, Furth SL, Neu AM, Fivush BA. Assessing associations between medication adherence and potentially modifiable psychosocial variables in pediatric kidney transplant recipients and their families. *Pediatr Transplant.* 2004;8(6):543-50. doi: [10.1111/j.1399-3046.2004.00215.x](https://doi.org/10.1111/j.1399-3046.2004.00215.x).
 19. Davis MC, Tucker CM, Fennell RS. Family behavior, adaptation, and treatment adherence of pediatric nephrology patients. *Pediatr Nephrol.* 1996;10(2):160-6. doi: [10.1007/bf00862061](https://doi.org/10.1007/bf00862061).
 20. Manificat S, Dazord A, Cochat P, Morin D, Plainguet F, Debray D. Quality of life of children and adolescents after kidney or liver transplantation: child, parents and caregiver's point of view. *Pediatr Transplant.* 2003;7(3):228-35. doi: [10.1034/j.1399-3046.2003.00065.x](https://doi.org/10.1034/j.1399-3046.2003.00065.x).
 21. 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):62-70. [Persian].
 22. Yosefi N. psychometric of scales McMaster Family Assessment approach. *Quarterly of Educational Measurement.* 2012;3(7):85-114. [Persian].
 23. Miller IW, Epstein NB, Bishop DS, Keitner GI. The McMaster Family Assessment Device: reliability and validity. *J Marital Fam Ther.* 1985;11(4):345-56. doi: [10.1111/j.1752-0606.1985.tb00028.x](https://doi.org/10.1111/j.1752-0606.1985.tb00028.x).
 24. 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](https://doi.org/10.1542/peds.2006-3470).
 25. Panahi F, Simbar M, Lotfi R, Rahimzadeh M. The effect of parents' training on their knowledge, attitudes and performance in exclusive breastfeeding up to four months: a randomized clinical trial. *Iran J Obstet Gynecol Infertil.* 2017;20(5):48-57. doi: [10.22038/ijogi.2017.9080](https://doi.org/10.22038/ijogi.2017.9080). [Persian].
 26. Alonso EM, Neighbors K, Barton FB, McDiarmid SV, Dunn SP, Mazariegos GV, et al. Health-related quality of life and family function following pediatric liver transplantation. *Liver Transpl.* 2008;14(4):460-8. doi: [10.1002/lt.21352](https://doi.org/10.1002/lt.21352).
 27. Sarabi Jamab M, Hassanabadi H, Mashhadi A, Asgharinekah M. The effectiveness of parent training on self-efficacy of mothers of children with autism. *Journal of Fundamentals of Mental Health.* 2011;13(49):84-93. doi: [10.22038/jfmh.2011.1027](https://doi.org/10.22038/jfmh.2011.1027). [Persian].
 28. Brownbridge G, Fielding DM. Psychosocial adjustment and adherence to dialysis treatment regimes. *Pediatr Nephrol.* 1994;8(6):744-9. doi: [10.1007/bf00869109](https://doi.org/10.1007/bf00869109).
 29. MacDonald H. Chronic renal disease: the mother's experience. *Pediatr Nurs.* 1995;21(6):503-7.
 30. Zhang S, Edwards H, Yates P, Li C, Guo Q. Self-efficacy partially mediates between social support and health-related quality of life in family caregivers for dementia patients in Shanghai. *Dement Geriatr Cogn Disord.* 2014;37(1-2):34-44. doi: [10.1159/000351865](https://doi.org/10.1159/000351865).