



# “Will My Child’s Illness be Cured?” Challenge of Parents whose Children Admitted to Nephrology Department with Chronic Kidney Disease: A Qualitative Study

## ARTICLE INFO

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## ABSTRACT

**Aims** This study aimed to examine the challenging experience of parents with hospitalized chronic kidney disease children in the nephrology department.

**Participants & Methods** Using the content analysis approach, a qualitative study was carried out on 19 parents with chronic kidney disease children. The participants were selected through purposive sampling. For data gathering, in-depth, semi-structured, and face-to-face interviews were carried out and the collected data were analyzed through conventional content analysis.

**Findings** Data analyses revealed two overarching categories of “confusion and the lack of support” and “chronic illness challenges.” The subcategories of category 1 were “insufficient information in parents and others” and “inadequate support.” Category 2 included the subcategories of “chronic nature of the disease” and “hard to manage the disease.”

**Conclusion** Through creating a proper communication and supportive environment, the health team members can significantly assist parents.

**Keywords** Chronic Kidney Disease; Children; Qualitative Research; Iran

## CITATION LINKS

[1] Chronic kidney disease ... [2] Epidemiology of chronic kidney disease in ... [3] Prevalence of chronic kidney disease ... [4] The effect of continuous care model on blood ... [5] Comparison of the sense of coherence between ... [6] Parental experiences and coping strategies ... [7] Parents’ satisfaction concerning ... [8] Reverence and morality-centered care ... [9] Frequency of medical malpractice claims ... [10] Healthcare service failure ... [11] Measurement of patient satisfaction as ... [12] Determinants of parental satisfaction ... [13] Nurses’ professionalism as a component ... [14] Parents’ experiences of family centred ... [15] The support needs of parents having ... [16] Parents’ experiences of living with a ... [17] Experience and meaning in qualitative ... [18] Data collection and sampling in qualitative ... [19] Qualitative content analysis in nursing ... [20] Epistemological and methodological bases of ... [21] Internet-based cognitive ... [22] Caregiver experience in pediatric ... [23] Silent screams: experiences of caregiver ... [24] Examining the roles and experiences of fathers ... [25] Identifying factors related to family management ... [26] Learning to live with nephrotic syndrome ... [27] Resilience model for parents of children with ... [28] Paediatric surgery for childhood cancer: Lasting ... [29] Child and family perspectives on adjustment ... [30] A metasynthesis: uncovering what is known ... [31] Families of children with chronic illness ... [32] Chronic anterior uveitis in children ... [33] Parental experiences of their infant’s hospitalization ... [34] Living with uncertainty and hope: a qualitative ... [35] Burden, depression and anxiety in primary ... [36] An interactive health communication application for supporting parents managing childhood ... [37] Compartmentalising time and space ...

## Introduction

As a serious health issue, chronic kidney disease (CKD) is on the rise worldwide [1]. The disease prevalence in children ranges from 15 to 74.7 cases in one million of the age-related population [2]. CKD has destructive effects on a variety of body systems [3]. Providing continuous care through cooperation between families and health systems can lead to higher life quality in the patients [4].

In the case of children with CKD, the primary caregivers are the parents [5]. The parents' and health care team's relationship and support positively impact parents' caregiving ability when their child is in the hospital and the recovery after discharge [6]. In addition, there is a relationship between the level of satisfaction the parents have about health care and the attenuation of the symptoms, recovery pace, following the treatment regimen, and comprehension of medical information by parents. The level of satisfaction in parents is a variable that can be used to examine the quality of care provided to the patient [7]. The increase in chronic cases, longer and more frequent hospitalization, and heavy healthcare expenses have created serious challenges in healthcare systems in the form of more cases of neglecting patients' rights and failure to provide care with respect [8]. There is a growing trend in the number of patients who are not satisfied with the quality of health care and this has negatively affected the relationship between healthcare personnel and patients [9]. Many patients complain about the quality of care they receive [10]. The level of satisfaction in patients with the care they receive is indicative of the quality-of-care services [11]. As a multidimensional concept, satisfaction with nursing and medical care is a function of the level of realized expectations in patients and families [12]. In the case of children as patients, parents are the authority who measure the quality of care [13]. Parents are entitled to have a role in health decisions and take part in the process [14]. Parents play a significant role in treating CKD children and their dissatisfaction negatively impacts children's health outcomes and medical treatment [15]. Thus, identifying parents' challenging issues by exploring their experience and addressing them could help manage the chronic conditions of the patient in the hospital [16]. To examine lived experiences of parents and realize the situation from their viewpoint, a qualitative study is the best approach [17].

This study aimed to examine the challenging experience of parents with hospitalized CKD children in the nephrology department.

## Participants and Methods

Following a content analysis approach, a qualitative study was carried out at Shahid Motahari Educational Hospital, Urmia-Iran. This hospital is

the only pediatric center in West Azerbaijan province, in northwestern Iran. The participants were parents with CKD children admitted to the nephrology department. The participants were selected through purposive sampling among the parents visiting the nephrology department, who met the inclusion criteria. Since the study environment is composed of ethnic minorities with different languages and cultures, ensuring the diversity of the participants. Thus, parents from different ethnic minorities were interviewed. But, since Persian is the official language of Iran, the interviews were conducted in Persian. To examine the candidates' ability to share their experiences, the authors had an informal conversation with them and also briefed the parents about the process and objectives of the study. In addition, they were informed that they can leave the study at any stage. Afterward, they gave their verbal and written consent to participate and voice recording during the interviews. The interview date was determined at their convenience. The interviews were held in the nephrology department in a private and quiet room. The interviews were held after the examination of the patient by a physician and the provision of nursing care during family visit hours. Totally, 19 parents were invited (13 mothers and six fathers) to the study and all accepted the invitation (19 parents of 17 CKD children). The inclusion criteria were the desire to participate, the ability to share experiences (parents), not a single parent, the child's diseases diagnosed more than six months ago, and no mental illness (parents).

For data gathering, interviews and field notes were carried out by the first author between September 2018 and September 2019. Before conducting the interviews, the researcher completed six credit hours in the qualitative research method and had a work experience in the nephrology department of a pediatric hospital. The researcher performed the first two interviews in presence of an adviser with the permission of the parents. After making the arrangements with the participants, a classroom in the nephrology department was used for holding the interviews. The participants were briefed about the study process, goals, and their roles in the study. They were also informed that their voice will be recorded during the interview. After participants signed a written consent form, the lead researcher carried out semi-structured, in-depth, and face-to-face interviews starting with an open-ended and general question along with deepening, exploratory questions. The research team developed the primary general questions through group discussion. The obtained questions were open-ended and using the responses, the rest of the interview would be followed. Some of the key questions were as follows: "how were the treatment and care provided to your child?" or "what experiences did you have during the hospitalization of your child?" Probing questions

were asked using the parents' answers: "what do you mean by that?" or "would you please explain more about that?" Each interview took about 20-60 minutes. The interviews were voice recorded as well. The interviews continued until data saturation – i.e. no new additional concepts were identified [18]. The study protocol was approved by the Research Ethics Committee, Urmia University of Medical Sciences. The participants were informed of the purpose of the study. Each participant signed written consent before participation. The lead researcher explained to them their voluntary nature of participation and that they can discontinue cooperation at any given time. The researcher also ensured the privacy and confidentiality of their information.

The interviews were transcribed verbatim and analyzed in MAXQDA 10. Through analyzing the interviews along with conducting further interviews, the main informant participants would be determined for the next interviews, which provided us with richer information. For data analysis, a conventional content analysis approach was conducted following Graneheim & Lundman [19]. This approach has six stages:

1. Immersion and identifying primary codes by reading the transcribed data;
2. Extracting primary codes in the transcript through line-by-line review;
3. Finding categories and sub-categories;
4. Reviewing categories to spot the relationship between categories and sub-categories;
5. Labeling categories and sub-categories; and
6. Developing the final report.

The lead researcher carried out the coding, and the rest of the team observed the coding process. Through exchanging ideas, the research team achieved an agreement as to the process of coding and categorizing.

To determine the precision and accuracy of the data, Lincoln & Guba's criteria were employed [20]. Long-term data engagement, member checking (participants), and peer checking (experts) helped us to improve the data credibility. A detailed report about the study process was made available and presumptions interrupting data collection and analysis were avoided. Through this, the authors improved conformability. To achieve dependability, a step-by-step repetition of the study process was carried out and external observers were allowed to audit, examine, and check the data and documents. The exact steps and activities of the study were explained to external reviewers to assure transferability.

## Findings

Totally, 19 parents of CKD children were interviewed including 13 interviews with mothers and six with fathers. Twelve parents had two children, six had one child, and one had three

children. Four parents had elementary education, six had a high school diploma, four had a bachelor's degree, and five had a middle school education. The children's illness term was between 7 months and 12 years.

This study reported two categories, four subcategories, and ten primary concepts derived from 210 primary codes. The first category was "confusion and the lack of support," which was supported by the subcategories of "insufficient information in parents and others" and "inadequate support." The second category of "chronic illness challenges" was obtained from the "chronic nature of the disease" and "hard management disease" subcategories (Table 1).

**Table 1)** Categories, subcategories, and primary concepts

Categories	Subcategories	Primary concepts
<b>Confusion and the lack of support</b>	Insufficient information in parents and others	The lack of information in parents about the disease Insufficient information about other family members
	Inadequate support	Inadequate family members' help and support Others blame the parents
<b>Chronic illness challenges</b>	Chronic nature of the disease	Relapse and hospitalization Aggressive and invasive treatment Disease with an unknown cause Unclear prognosis
	Hard management disease	Caring for a child with a catheter at home Continuous monitoring

## Confusion and the lack of support

### Insufficient information in parents and others

-The lack of information in parents about the disease: Lack of information about CKD, treatment options, child care, diet, medication preparation, etc., are some common problems that parents face, making it difficult for them to decide about their child care and treatment. Regarding the lack of information about the medication preparation, one participant said:

*"The physician said that you can find the medicine in Turkey, and then my husband checked every pharmacy in the city but he was not able to find it. It was the first time that we had this problem. We do not know where to find it."* (P.13)

-Insufficient information from other family members: The participants reported that other family members were not aware of CKD and had too little information about it. In some cases, this lack of information made them not take the disease seriously, and this upset the parents of children with CKD. One parent shared her experience as follows:

*"My sister-in-law always forgets that salt is not good for my son and she adds salt to every meal she prepares for us."* (P.10)

### Inadequate support

-Inadequate help and support by family members: In addition to other problems, the lack of family members' help and support, both mentally and practically, can make the difficult situation worse for the parents and it is more likely to negatively impact parents' adaptation to their child's disease. Participant 10 voiced:

*"My husband asked his family members for help to send our children abroad for medical treatment, but they did not support us, even though they could."* (P.10)

-Blaming the parents by others: Some participants stated that being blamed by other family members for their child's condition was the most disturbing experience they ever had. One of the parents said:

*"My husband always blames me and says, it's your fault. You did not take good care of our child. If you had so, she would not have the disease."* (P.9)

### Chronic illness challenges

#### Chronic nature of the disease

-Relapse and hospitalization: According to the participants, due to CKD progression's insidious nature, it becomes even more challenging to control it over time. The parents' or the child's negligence can lead to relapses and hospital readmissions. One parent said:

*"...my son has been under the supervision of a doctor and taken the medication since then. He has been hospitalized nearly 20 times over the last 4-5 years."* (P.15)

The hospitalization term depends on the medical treatments. One participant talked about this challenge as follows:

*"...my child started to complain of sudden abdominal pain one and half years ago. I took him to the hospital, and doctors found 19 small stones in his left kidney, and my child was hospitalized for six consecutive months."* (P.2)

-Aggressive and invasive treatment: Some participants reported that children sometimes undergo aggressive diagnostic procedures to reach a definitive diagnosis. Sometimes the treatment of this disease, like its diagnosis, requires aggressive measures. Participant 7 said:

*"When he was six years old, his creatinine was slowly rising. A nephrostomy was performed to remove the pressure from his kidneys. My poor son suffered a lot."* (P.7)

-Disease with an unknown cause: Participants also described that they were not aware of the cause of the disease and its recurrence. So, they worry all the time. One mother shared her experience as follows:

*"When I asked the doctor why my son is sick, the doctor said that his disease is of an unknown origin, and they have not yet discovered a specific cause of it. I searched the Internet to find what causes*

*CKD and found out that the kidneys' function is weakened."* (P.10)

-Unclear prognosis: Another problem stated by the most of participants was the prognosis of this disease of unknown origin. Uncertainty about the future of the disease and ambiguities about the child's life can confuse the parents and make them lose their composure. One parent voiced his concern as follows:

*"The medications that my child takes can't cure her illness and only control the symptoms; this is a stressor to us. Will my child's illness be cured? How long should she take this medication? Only God knows!"* (P.13)

### Hard management disease

-Caring for a child with a catheter at home: Some participants requested to take their child home while having catheters, such as a Foley catheter, peritoneal dialysis catheter, nephrostomy catheter, etc., which required them to take care of a child with a catheter at home. One of the parents said:

*"My child has had three surgeries. Both of his kidneys have been opened in the surgeries. With a nephrostomy catheter inserted through his skin into his kidneys, they asked me to take him home from the hospital while having a nephrostomy catheter. I have been taking care of my child with a catheter at home for a month now."* (P.7)

-Continuous monitoring: Some participants believed that observation and continuous monitoring were required to look after a child with a catheter at home. In the case of any problem, immediate action is needed in the first few days, and a delay in treatment may make the condition worse and more difficult to treat. A mother voiced:

*"The kidneys are very sensitive. This time, for example, she had a urinary tract infection. Her infection was not severe enough to enter her kidneys. If I had found out too late, it would have affected her kidneys."* (P.4)

### Discussion

The experiences of parents during the CKD children's hospitalization were studied. The data analyses demonstrated the challenges that parents had to face because of their child's illness. After receiving an initial diagnosis, the parents would face tough situations, such as the child's illness and lack of information. Our findings are consistent with other studies suggesting that parents required more extensive information as to their child's CKD and treatment options [15, 21, 22]. Parents need to be informed about their child's illness to be able to look after the patient, make their own good decisions, and support their children. The information helps parents gain knowledge about their child's illness and have a clear understanding of the situation. It also reduces parental confusion and helps them to

keep their composure. In addition to the parents, other family members have too little information about CKD. Family members unfamiliar with this disease tend to display unsupportive behaviors. In a study conducted by Abedi *et al.* [23] parents of children with thalassemia also suffered from the disease's unknowingness, the lack of public awareness, and being blamed by other family members for their child's condition.

After hospitalization, in addition to the lack of necessary information, the lack of practical and emotional support for the parents caused parental confusion and intensified the sense of loneliness and inability to cope with their child's illness. Parents of chronically ill children have very few resources to support their children [15, 16, 23, 24]. The results of a study conducted by Zhang *et al.* [25] showed that social support was a moderator. They also highlighted the need for effective interventions like emotional support to help the parents adapt to the situation. The present study results are consistent with previous studies showing that parents of children with chronic diseases need practical and emotional support and also information about the disease. Otherwise, they may feel confused and lonely in such situations. Therefore, in addition to paying attention to all the needs of these parents, the healthcare staff should use effective creative strategies to promote positive aspects of caring for caregivers of children with a chronic disease and reduce the gaps that can prevent parents from being positively adapted to the illness of their child. In addition to these problems, blaming the parents by other family members for their child's condition is another issue that can make them feel upset. In line with this study, blaming the parents by other family members for their child's condition was also revealed in a study [23]. Being blamed by other family members for the child's condition can also cause psychological trauma in the parents and harm parental adjustment, making it essential to provide more emotional and psychological support to them. The participants felt worried and experienced long-term stress and mental and physical exhaustion due to long-term illness or chronic condition and disease recurrence, and the child's need for frequent hospitalization and continuing care. In their study, Beanlands *et al.* [26] showed that the complexity of nephrotic syndrome in children and its treatment can arise challenges to parents' decision-making about child care. According to Zhang *et al.* [25], compared to those with other conditions, parents of children with kidney disease need more effort to manage the situation. Recurrent hospitalization of chronically ill children can lead to poor adaptation for families. Ye *et al.* [27] demonstrated that frequent hospitalizations and an unpredictable course of childhood cancer could result in parental depression. Avaznejad *et al.* [5] found that the diagnosis and long-term treatment of children with

chronic disease had hurt mothers' sense of coherence. The nature of the disease and its problems are some of the challenging factors influencing the families' adaptation that cannot be altered through interventions. Facing aggressive treatments is difficult or painful for parents with a chronic disease and it is often accompanied by the child's lack of cooperation in early disease progression. This poses considerable challenges to parents and exacerbates the problems. Gabriel *et al.* [28] showed that children with cancer need aggressive treatments which can cause parenting stress and mental health problems. In their study, Easterlin *et al.* [29] demonstrated that anxiety during intravenous line placement was one of the challenges faced by parents of children with inflammatory bowel disease (IBD).

The unknown etiology and prognosis of the disease and parents' concerns over their child's future were other study findings. One of the challenges experienced by the parents of children with IBD is the unpredictable nature of the disease [29]. A study by Bally *et al.* [30] indicated that parents of children with life-threatening illnesses experienced deep uncertainty (i.e., parents' concerns over their child's future). Pate *et al.* [31] demonstrated that parents' daily lives can be interrupted by chronic diseases of children with an unknown prognosis and treatment and this can threaten the whole family system. Parker *et al.* [32] concluded that fear of the future is also reported by parents of children with chronic anterior uveitis. In a study performed by Kosta *et al.* [33] parents of CHD children undergoing cardiac surgery reported the problems due to the unknown etiology of the disease, surgery, and recovery. In their study, Abedi *et al.* [23] found that parents of children with thalassemia suffered from the unknowingness of this disease and uncertainty and that they had concerns about their child's future. Uncertainty was reported in parents of children with chronic diseases in recent studies [34, 35]. In order to eliminate the uncertainty and control the uncertain situation experienced by parents, healthcare staff can implement interventions focused on providing sufficient information about the disease and strategies to meet the childcare needs. Parents of CKD children have a major role in managing their child's illness at home. Managing their child's health problems at home, continuous monitoring, and interventions can pose a wide range of challenges to the parents, especially when they do not have the necessary information about the interventions [36].

The participants mentioned their concerns about providing care to a child with a catheter at home and its problems. Wightman *et al.* [22] indicated that parents were considered an enforcer of medical limitations on diets, fluids, medications, and dialysis at home. Another finding of the study was that these children need strict discipline and continuous supervision. Parents of children with CKD need

more effort to manage the situation [25]. Research works have indicated that the care for CKD children may be stressful and tedious for the parents, and dialysis is a complex and time-consuming treatment [21, 37]. In addition, parents who provide care for thalassemia children tolerate a great burden including stress [23]. Parents who provide care for children undergoing dialysis have many responsibilities [22]. Given the complexity of care required by children with CKD, parents need more support to manage the disease and adapt to the situation.

The fathers were far fewer than the mothers in the study, which is a limitation. This can be due to the major role of mothers in providing care to their children in the hospital and that fathers have to work and have less free time to be with their children in the hospital. Including a larger group of fathers in future works is recommended.

## Conclusion

The lack of information and support and the nature of managing the chronic disease can intensify the child and parents' problems. The health team can have a significant role in creating efficient communication and support and providing the parents with the needed information as to the disease and the necessary care to alleviate or solve such problems. Parents of CKD children also require organizational and social support to easily overcome the problem caused by the chronic nature of the disease. The health organization can support parents by holding stress reduction classes. The family and relatives can also help the parents in this challenging and overwhelming path toward adaptation by providing financial and emotional support.

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**Authors' Contributions:** Hemmati MaslakPak M (First Author), Introduction Writer/Methodologist/Main Researcher/Statistical Analyst/Discussion Writer (25%); Parizad N (Second Author), Introduction Writer/Methodologist/Assistant Researcher/Statistical Analyst/Discussion Writer (25%); Feizi A (Third Author), Introduction Writer/Methodologist/ Assistant Researcher/Discussion Writer (25%); Khorsandi F (Forth Author), Introduction Writer/Methodologist/Main Researcher/Statistical Analyst/Discussion Writer (25%)

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