

The voices of parents whose children hospitalized with chronic kidney disease: A qualitative study

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Research article

Keywords: Experience, Health Care Providers, Parents, Chronic kidney disease, Qualitative Research, Iran

Posted Date: May 11th, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-26956/v1>

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Abstract

Background

Parents play an important role in the treatment of children with chronic kidney disease (CKD) and their dissatisfaction may result in negative impacts on children's health outcomes as well as their medical treatment. Thus, exploring parents' experience and identifying and addressing challenging issues could be helpful in managing the patients' chronic conditions during their hospitalization. This study aimed to explore parents' experiences during the hospitalization of their children with CKD.

Methods

This study was a qualitative study with the content analysis approach. Participants were 15 parents of children with CKD who were selected by purposive sampling. Data were collected using in-depth, semi-structured, face-to-face interviews. Data were analyzed using conventional content analysis.

Results

Two overarching categories of "improper behavior of personnel" and "unprofessional performance of personnel" were extracted from the data. The first category included sub-categories of 'staff aggression' and 'staff indifference'. 'Disturbed interaction', 'poor patient care, and 'poor skills of personnel' were considered as the sub-categories of "unprofessional performance of personnel".

Conclusion

The results indicated that improper behavior and unprofessional performance of the healthcare personnel can intensify the child's and parents' problems, and make it more difficult for them to deal with these difficulties. The medical team can significantly help parents by establishing appropriate communication and behavior, providing them the required information about their child's disease and the necessary care to mitigate or eliminate their problems. Also, health care authorities can develop and implement educational and practical guidelines for healthcare personnel to improve their knowledge and skills.

Background

Chronic kidney disease (CKD) is one of the major health issues and it is on the rise worldwide [1]. The prevalence of CKD is 1.5-3 cases per 10,000 among children under 16 years old [2]. This disease has destructive effects on different systems of the body [3]. Providing continuous care can improve the quality of life in these children [4], and it requires the involvement of health systems and families [5]. Parents are primary caregivers to a child suffering from CKD [6]. The relationship of the health care team and their Support have a positive impact on the caregiving ability of parents during hospitalization and

the improvement of the child's recovery after discharge [7]. Moreover, improving children's health or reducing their symptoms, adhering to their treatment regimen, and parents' understanding of medical information is linked to the parents' satisfaction with health care. Parents' satisfaction with health care may be used as an appropriate variable to assess the quality of patient care [8]. Growing the number of chronic diseases, higher hospitalization rates, and huge health care costs have encountered health care systems with major challenges such as paying less attention or ignoring patients' rights and not treating the patients with proper respect [9]. The number of patients who are disappointed with medical services is in the rise globally and it damages the link between patient and healthcare providers [10]. The majority of patients are dissatisfied with the quality of medical services [11]. The quality of medical services is equal to a sense of satisfaction in patients regarding care and treatment [12]. Satisfaction with medical and nursing care is a multidimensional concept and depends on the degree of meeting expectations of the patients and their families [13]. When the patient is a child, the satisfaction with medical care is evaluated by parents [14], who have the right to be part of the medical team members and participate in the medical decision-making process [15]. Parents play an important role in the treatment of children with CKD and their dissatisfaction may result in negative impacts on children's health outcomes as well as their medical treatment [16]. Thus, exploring parents' experience and identifying and addressing challenging issues could be helpful in managing the patients' chronic conditions during their hospitalization [17]. Qualitative study is the best approach to reach the lived experiences of parents and understand the situation from their perspective [18]. This study aimed to explore parents' experiences during the hospitalization of their children with CKD by using a qualitative research approach.

Methods

Study Design And Setting

This qualitative study was conducted using the content analysis approach in Shahid Motahari teaching hospital of Urmia in Iran.

Participants

Participants were 15 parents (9 mothers and 6 fathers) of children with CKD who were hospitalized in the Nephrology department. Participants were selected using purposive sampling and a snowball approach was used to find informant participants. Similar to other qualitative studies, the sample size was based on data saturation. In this study, data saturation occurred when previously collected data were repeated during interviews and no other new codes were obtained. Inclusion criteria included willing to participate in the study, having the ability to express experiences, more than 6 months had passed since a child's diagnosis, not being a single parent, and not having a mental illness in the parents.

Data Collection

Data collection was performed through interview and field notes by the lead researcher (Ph.D. candidate) from September 2018 to September 2019. She had passed 6 credit hours of qualitative research methodology class before the interview. She owned a master's degree and worked in the Nephrology unit in the pediatric hospital. She was interested in the research topic and she performed the first two interviews with her advisor after obtaining permission from the participants. Upon agreement of the participants, meetings were held in the classroom of the Nephrology unit. The researcher explained the research process, objective, and the roles of the participants in the study. She obtained written consent from participants and notified them about recording their voice during interview sessions. She performed in-depth, semi-structured, face-to-face interviews, and started with a general, open-ended question, followed by exploratory, deepening questions. The research team discussed and developed primary general questions. The questions had open and interpretive answers and participants' responses guided the research process. The main questions of the interview were as follows: "how were the treatment and care provided to your child?" or "what experiences did you have during the hospitalization of your children?" Based on parents' answers, probing questions were asked: "what do you mean by that?" or "would you please explain more about that?" Each interview lasted for approximately 20–60 minutes. A digital voice recorder was utilized to record each interview. Data collection continued until data saturation was reached [19].

Data analysis

Each interview was transcribed verbatim and analyzed by using MAXQDA 10 software. Simultaneous analysis of the interviews provided access to the key informant participant for the next interview and lead to obtaining richer information. Data analysis was carried out using the conventional content analysis approach suggested by Graneheim and Lundman [20]. This approach includes 6 stages: 1) becoming familiar with transcribed data through immersion and identifying primary code by reading, 2) generating primary codes in the transcript by reviewing line by line, 3) searching for and recognizing categories and sub-categories, 4) reviewing categories to find the relationship between categories and sub-categories, 5) naming and labeling categories and sub-categories, 6) preparing the final report of the analysis. In this study, the leading researcher performed coding and the other research team members monitored the coding process. The research team member spent exchanging ideas until they reached an agreement about coding and categorization processes.

Rigor

Lincoln and Guba's criteria were applied to determine the precision and accuracy of the data [21]. Prolonged engagement with data, peer checking (expert review), and member checking (participants' feedback) were performed to increase the credibility of the data. The researchers tried to provide a detailed report of the research process and prevent the researcher's presumption from interfering with data collection and analysis in order to achieve Conformability. Dependability was achieved by step by step repetition the research process, and allowing external reviewers to audit and critique the data and

documents. To assure transferability, the steps and activities performed during the research process were described precisely and confirmed by external reviewers.

Results

Demographic profile of participants

The results were obtained from interviewing 15 parents of children with CKD. Nine of them were mothers and six were fathers. Seven parents had two children and eight of them had one child. Four parents had primary education, two held a high school diploma and nine of them had bachelor’s degrees. The duration of a child’s illness ranged from 7 months to 12 years.

Categories

Two overarching categories of “improper behavior of personnel” and “unprofessional performance of personnel” were extracted from data. The category of improper behavior of personnel” had sub-categories of ‘staff aggression” and “staff indifference”. "Disturbed interaction", "poor patient care", and "poor skills of personnel" were considered as the sub-categories of "unprofessional performance of personnel" (Table 1).

Table 1
Categories, subcategories and primary concepts of the study.

Categories	Sub-categories	Primary concepts
Improper behavior of personnel	staff aggression	- Health professionals’ irritability - Non-clinical staff short temperedness
	staff indifference	- Inattention to parents’ awareness - No attention to parents’ concerns
Unprofessional performance of personnel	Disturbed interaction	- Lack of providing information to parents - Lack of easy access to the doctor
	Poor patient care	- Ignoring patients' problems - Lack of providing care in a timely manner
	poor skills of personnel	- Improper diagnosis and treatment by some physicians - Poor skills of some nurses - Poor skills of some non-clinical personnel

Improper behavior of personnel

Staff Aggression

Health professionals' irritability

Participants mentioned doctors' anger as a communicating obstacle in hospital. Some parents said that they were afraid to ask them questions about their child's condition. Participant 6 said:

"...my husband keeps telling me to ask his doctor about his condition to see how it's going. I told him, I can't ask his doctor much; he gets upset so easily. Actually, that's how he is. I can't ask him much..." (P.6)

Some parents complained about inappropriate behavior by some nurses. This is how one of the parents described her experience in this regard:

"...I asked her (my daughter's) nurse a question, she did not answer me and got angry. She told me "I do not know anything about your child, just ask her doctor..." (P.1)

Non-clinical staff short temperedness

Some parents were upset with non-clinical personnel such as housekeepers. One of the parents mentioned:

"... my son was eating something, a bit of his snack dropped on the floor. The housekeeper got mad and yelled at him..." (P.6)

Staff Indifference

Inattention to parents' awareness

Participants voiced that some of the physicians paid no attention to parents' level of understanding with medical terminology when answering their questions. Participant 3 voiced:

"...The doctor said: 'Mr. ..., we would give your child Albumin, his cholesterol level has gone up and his glucose has gone down.' He thought I was a doctor like him or I was one of his colleagues. And I was stumped and said thanks Dr. ... later I would wonder: 'what's glucose, what's cholesterol...' (P.3)

No attention to parents' concerns

A few of the participants noted that some doctors and nurses refused to answer parents' questions and ignored their concerns. One of the parents stated:

"... The pediatric resident told us to take lab results to my professor urgently. He should see this immediately... The professor was at a conference. It was winter. I was really worried and sat in front of the conference hall in the yard for one and a half hours. After the conference was over, the professor came out. I said, 'dear professor, this is my kid lab report ... the resident said you should see this...' He didn't take

a look at the report and said, 'The resident should read the lab report for me and I'll give the answer to him, not to you...'" (P.7).

Unprofessional performance of the personnel

Disturbed Interaction

Lack of providing information to parents

In this study, some participants stated that they were not provided the necessary information about their child's disease and their treatment process. This unawareness made it difficult for parents to make decisions about their child's treatment and caused them great anxiety and concerns. A mother shared her experience as follows:

"They gave me a brochure and it's just some simple information about the disease. I asked my child nurse to give me some information about her diet, activities, etc. The nurse told me to check out the internet, you can find everything online" (P.6).

Lack of easy access to the doctor

According to the participants, it was extremely difficult to visit the attending doctors in the hospital. Some of them voiced that the residents and interns come and visit the patients. Sometimes, if we have questions about our child's condition, we have to wait several days to see the doctor. One of the parents stated:

"It's been 3 days now I haven't seen her doctor yet. Some other doctors came and saw my kid. When I ask them 'how I can visit her doctor. They just say, he will be here any minute'..." (P.13)

Participant 7 shared her experience as follows:

"His doctor referred us to a doctor in Tehran. We passed through a Herculean task to see the doctor. At first, a resident visits my child, then a surgeon saw him. It took us about 2 hours until we finally reached the doctor..." (P.7).

Poor Patient Care

Ignoring patients' problems

Some of the parents experienced poor quality of patient care in the hospital. They complained that their child problems were ignored by some of the healthcare providers. A mother stated:

“... I said to the nurses that my son wasn’t feeling all right at all and asked them to come and check on him. Once my son felt extremely bad and started having a seizure... I shouted ‘someone please help me...’” (P.1)

A father shared his experience as follows:

“... My wife shouted ‘oh, God, my child died, someone please help him.’ I fought the security man, he didn’t let me in. I rushed into the department. They checked his blood pressure; it was 4. I said, ‘for God’s sake, we are here since this morning; Sister, you didn’t even check on him.’” (P. 5)

Lack of providing care in a timely manner

Some participants complained about the lack of timely care services and medical interventions based on previous scheduling, as one of the parents stated:

“... They told us to be here at 8 in the morning for surgery. We stayed in a hotel the night before and went to the hospital early in the morning. We sat in the waiting room until 1 PM. My child was sitting there with an empty stomach all that time. The doctor finally showed up at 1...” (P.7).

Poor Skills Of Some Healthcare Personnel

Improper diagnosis and treatment by some physicians

Some parents were dissatisfied with the primary inappropriate diagnosis and treatment by some physicians. The parents talked about their experience as follows:

“... She was being under her doctor’s supervision for two years. The other day, I saw that her eyes had become sunken and her body had been terribly dried. We are here now and the doctor said the dose of her medications has to be adjusted before she discharges home...” (P.6).

“... His feet were swollen little by little, his hands, his face, and every part of his body was swollen; he had become like a ball. Then, we took him to the clinic. They said ‘it is because of his cold and you don’t have to worry about it. It will be OK’. He got worse and hospitalized...” (P.11)

Poor skills of some nurses

Some parents were disappointed with the poor performance of nurses that had caused pain and discomfort in their children. Regarding this issue, Participant 13 stated:

“When we were in the emergency department. A nurse tried to insert her IV catheter, she tried several times but didn’t succeed. She still wanted to try one more time. I said, Oh! ma’am, you made a lot of holes in my child’s hand. Please, ask someone else to come.” (P.13)

Poor skills of some non-clinical personnel

Some parents complained that incorrect laboratory test results and poor performance of radiology staff caused them extreme anxiety. Participant 5 and 7 describe their experience:

“... After I got the lab results. Laboratory technician told me, one of his results was too high. We were under great stress because of this test result. We saw his doctor and re-checked the test...It was 83 and the doctor said it wasn't high at all...” (P.5).

“After surgery, they moved him to ICU. Then, the doctor came and ordered radiology imaging. After the imaging was done, they gave the image to the doctor. He said it didn't show anything. He said they had used –I don't know– too little or too much of rays. He got upset and said imaging should be repeated...” (P.7).

Discussion

This study was carried out to explore parents' experiences during the hospitalization of their children with CKD. Results indicated that the parents had experienced inappropriate behavior and unprofessional performance of the healthcare personnel. Staff indifference and aggression were the behaviors that parents faced during their children's hospitalization. Our findings are confirmed by the following studies. Reader and Gillespie (2013) reported that patients and their families believed that healthcare personnel ignored their feelings and physical health [22]. Another study showed that 37 cases per 1000 patients experienced indifference during their hospitalization [23]. Robinson et al (2014) indicated that patients complained about the lack of healthcare personnel's sympathy [24]. According to Schnitzer et al study (2012), patients complained about not being involved in medical decision making and lack of personnel's empathy [25]. Montini et al (2008) showed that one of the patients' complaints was “patient not taken seriously” [26]. Indifference to the patients and their family members is a problem related to the attitude of the health care providers. This problem has been reported frequently in healthcare facilities and can hurt patients or cause unpleasant clinical consequences. Thus, health policymakers need to investigate this problem and take the necessary steps to solve it.

Staff aggression was another behavioral problem mentioned by the participants in our study. The following studies are in line with our study. According to a study by Schnitzer et al (2012), health care unfriendly behavior and disrespect were as patients' complaints [25]. Harrison et al (2016) showed that lack of respect and dignity was the hospitalized patients' complaints [27]. Skálén et al (2015) claimed that 34.6% of patients' complaints were about the communication and attitude of health care providers [28]. Henderson et al (2009) found that many ethical principles and patients' dignity were not met during healthcare activities [29]. When caring for patients, observing ethical principles, and treating the patients with respect, dignity, and compassion determine the quality of care in health care facilities. Aggressive and unethical behavior of the health care team can cause problems for both patients and healthcare providers. The medical team must consider ethical principles when providing care for patients. To reach this goal, constant training should be offered to the medical team members.

Disturbed interaction was another finding of our study. The interactive problems between the medical team and parents cause issues in health care providers and the treatment process. If the medical team has defective interaction with parents and provides them insufficient information about their children, it can lead to complications and delayed treatment in their children. Limited studies have been conducted on this topic. Asadi Noghabi et al (2004) claimed that the vital mission of patient education is not performed well, and because of this issue, not only the patient but also their family and society suffer [30]. Mazor et al (2012) reported that patients attributed 47% of the problems to communication difficulties, including information exchange issues [31]. In Robinson et al study (2014), patients were dissatisfied with an inadequate explanation about the treatment options [24]. Schnitzer et al (2012) showed that the patients' dissatisfaction was due to the lack of diagnostic and medical information [25]. Montini et al (2008) reported that patients were disappointed with insufficient information, staff's inattention, and inappropriate responses to their questions [26]. Proper interaction of the medical team with patients can lead to positive treatment outcomes. The inability of the medical team to properly interact with patients caused problems, including the negative attitude of patients toward the health care providers, increased patient dissatisfaction, patient noncompliance with treatment, and even change of the doctor. Healthcare staff can help expedite the successful treatment of patients through improving proper interactions with patients.

Parents had experienced poor patient care in our study. They voiced that their patients' problems were ignored and the care was not provided on time. Similar to our findings, delayed diagnosis and treatment [27, 31], late medical procedures [27], long waiting times for medical procedures [24, 26, 27], and incorrect test results/analysis [26] were among the patients' complaints in various studies. Poor patient care may lead to non-compensable consequences for patients. As a result, the healthcare system must identify the underlying causes and take necessary actions to avoid this issue.

Lack of the required skills in health care providers was another issue as discussed by the participants in our study. The findings indicated that late and incorrect diagnosis and malpractice by some physician, surgical misoperation by some inexperienced residents, and poor performance of procedures by some nurses and other department technicians caused complications in children, and intensified parents' distress and dissatisfaction. Parallel to our finding, a recent study reported that misdiagnosis causes about 40,000–80,000 deaths in US hospitals, annually [32]. In the study by Robinson et al (2014), patients of a fertility center had complaints about incorrect semen analysis reports [24]. Skálén et al.'s study (2015) also indicated that 59.1% of the complaints were related to healthcare/medical treatment [28]. In addition, misdiagnosis, poor skills, lack of knowledge and work experience, carelessness, and negligence of health care providers were reported in previous studies [27, 33, 34]. These results are in line with our findings. Lack of competence and skill in healthcare providers can have negative impacts on patients' treatment. Medical team members should make an effort to acquire and enhance their knowledge and skills needed to care for patients in order to avoid harm to themselves and the patients.

Study limitation

The low number of fathers' participants compared with mothers was one of the limitations of this study. Possibly because of the significant role of mothers in caring for the child in the hospital, fathers' workload and not being able to present to the hospital. Thus, it is recommended to engage a higher number of fathers in similar future studies.

Conclusion

The results of this study indicated that improper behavior and unprofessional performance of the healthcare personnel had intensified the child's and parents' problems, and making it more difficult for them to deal with these difficulties. The medical team can significantly help parents by establishing appropriate communication and behavior, providing them the required information about their child's disease and the necessary care to mitigate or eliminate these problems. Also, health care authorities can develop and implement educational and practical guidelines for healthcare personnel in order to improve their knowledge and skills.

Abbreviations

Chronic kidney disease (CKD).

Declarations

Ethics approval and consent to participate

This study was registered and approved by the ethics committee of Urmia University of Medical Sciences (IR.UMSU.REC.1397.138). The researcher informed all participants about the voluntary nature of their participation and that they have the right to terminate their cooperation with the researcher at any time during the research process. They were also given an explanation about the purposes of the research and assured about their privacy and confidentiality of their information. All participants signed informed consent before participation.

Consent for publication

Written informed consent was obtained from the patient for publication.

Availability of data and materials

The datasets used and analyzed during the current study are available from the corresponding authors on reasonable request.

Competing interests

The authors declare no conflicts of interest.

Funding

This study was supported by Grant from Urmia University of Medical Sciences, Iran

Authors' contributions

All authors (Fatemeh Khorsandi, Naser Parizad, Masumeh Hemmati MaslakPak, and Aram Feizi) have actively participated in this study. Design of the study FK, MHM, NP, AF; data collection: FK, MHM; analysis and interpretation of data: FK, NP, MHM, AF; manuscript preparation: FK, NP, MHM, AF; manuscript revision: NP, AF, MHM. All authors read and approved the final manuscript before submission.

Acknowledgments

This study is derived from the Ph.D. dissertation in nursing. The authors would like to appreciate the support of Vice Chancellor for Research of Urmia University of Medical Sciences. They also wish to thank all the parents of children with CKD without whom, this study would not have been possible.

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