

Experience of Mothers Having Children with Chronic Kidney Diseases: A Qualitative Study

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Abstract

Objectives: To explore the experience of mothers having children with chronic kidney diseases in Nephrology department of Government Hospital Bahawalpur. **Method:** This research utilized a qualitative phenomenological research methodology to explore the experiences of mothers caring for children with chronic kidney disease (CKD). The researcher recruited mothers with firsthand experience in caring for their children with CKD. Data collection involved conducting interviews with twelve mothers of CKD-afflicted children. The researcher conducted these interviews to elicit in-depth information from the participants. Subsequently, each interview was transcribed by the researcher. Upon completion of the transcription process, the researcher manually assessed the data. Thematic analysis was employed, resulting in the categorization of findings into four overarching themes. The researcher utilized thematic analysis to identify various themes and sub-themes emerging from the interviews. **Results:** To determine the findings themes were generated. The researcher identified four broad themes, as Emotional impact, coping mechanism, impact on family dynamics and Financial Challenges faced by the parents of children having chronic kidney diseases. These themes were further divided in various subthemes such as Initial Shock and Uncertainty, Confusion between hope and despair, Anxiety and panic among Mothers, Seeking Information and Education, Building Support Networks, Worries about effects on family, Medical Expenses and Treatment Costs and Impact on Employment and Income etcetera. **Conclusion:** This research is inquired an overall experience and challenges faced by mothers who were taking care of their CKD children.

Keywords

Chronic Kidney Disease, Mothers Experience, Qualitative Study.

Chronic Kidney Disease (CKD) is also known as chronic kidney failure, is a condition in which the kidneys are unable to excrete blood waste products or extra fluid from the blood (1). Chronic Carney Kidney Disease is considered the 12th leading cause of death. Worldwide, approximately 697.5 million cases were reported with Chronic Kidney Disease with prevalence of 9.1% (2). CKD affects all ages. The prevalence of chronic kidney disease is not only high in the adult population but also in the pediatric population. Worldwide, the prevalence of chronic kidney disease among the pediatric population is approximately 18.5-58.3 per million children. The unbearable complications and associated diseases with chronic kidney disease may have a huge impact on the mortality and morbidity rate among children. Similarly, the mortality rate is 30 times higher in the pediatric population as compared to the adult population (3, 4).

Likewise, other developed and developing countries, the

prevalence of chronic kidney disease in Pakistan is also very high. The overall chronic kidney disease prevalence among Pakistani population averagely was 21.2% with the highest chronic kidney disease prevalence in Pakistan was reported as 29.9% and the lowest prevalence was 12.5%. Similarly, the pediatric population also reported high statistics (8.12 per million) of Chronic Kidney Disease in Pakistan (5). The most common treatment modality of chronic kidney disease among pediatricians is hemodialysis. Hemodialysis is a complex and multidisciplinary treatment. It is usually performed twice a week and one session takes four to five hours. In addition to the hemodialysis, the patient needs nutritional supplements, blood transfusion. The arteriovenous fistula (AVF) needs extra care at the hospital as well as in the home (6).

The disease itself and the treatment may also carry a variety of complications in children. The common complications of Chronic Kidney Disease and hemodialysis are hyperkalemia,

hypertension, anemia, proteinuria, acidosis, metabolic bone diseases, growth failure, cognitive impairment, infections, arteriovenous fistula malfunctioning, and bleeding (7). The curable rate of chronic kidney disease among the pediatric population is also very low. The children and their families experience a very tough time facing the disease complications and treatment. Usually, the disease goes through a longtime treatment such as dialysis or another treatment option of kidney transplantation. Both the treatment options have severe complications such as infection, and other associated complications that prolonged hospital stay (7, 8).

The severity of complications, comorbidities, and life expectancy depends on the treatment provided to the children. The care to the children with chronic kidney disease is not only provided in the health care setup but these children are equal treatment in homes. The role of caregivers is very important to provide good and standard care to these children. Effectively management of children with Chronic Kidney Disease not only overcomes the symptomatic burden of disease but also prolongs the life expectancy of patients (9, 10). The children are always dependent on their mothers. The mothers are involved in the direct and indirect care of the children. The mothers are usually involved in direct care such as hygiene care, medication, feeding, care of fistula, and symptomatic care. The fathers are usually involved in indirect care such as financial support and hospital care (11). Children with Chronic Kidney Disease undergo through prolong treatment. Most of the care is provided in the home. In the hospital setting only symptomatic and hemodialysis are performed (12).

The prolonged treatment, variety of complications, dependability of the children, and increase care burden not only impact the mothers physically but also impact the mothers psychologically (13). Dealing with these entire complications and problems, the mothers of the child adopt the extra role of health care professionals (14, 15). Studies reported that mothers of children with Chronic Kidney Disease experience poor quality of life. Being a central role, the mothers impact their health by providing different interventions at home, dealing with frequent dialysis, prolonged medication, and delivering nutrition supplements. Also, the mothers of children with Chronic Kidney Disease reported poor QOL (Gayomali et al., 2008; McKenna et al., 2006). Besides, the mothers of a child with chronic kidney disease also experience mental health issues. The literature highlighted the experiences of mothers and revealed that the mothers of children with Chronic Kidney Disease experience stress, fatigue, disrupted peer relationships, bonding, financial issues, restriction in daily life activities, and difficulty fulfilling daily life activities (Failure & Hemodialysis, 2018; Noran M Abu-Ouf, Albaraa Sumeer Abualhamyl, Nouf Fahad AlJahdali, 2016; Allison Tong et al., 2008).

Material and Methods

The study utilized a qualitative phenomenological design

to examine the experiences of mothers caring for children with chronic kidney disease in the Nephrology department of the Government Hospital in Bahawalpur, Punjab. Focused on mothers of pediatric patients with chronic kidney disease, data collection included approaches during follow-up checkups and hemodialysis in the Nephrology unit, encompassing outpatient departments and the dialysis unit. Participants meeting inclusion criteria were selected through specific questions, with clear communication about the study's objectives, emphasizing its non-financial and voluntary nature. Confidential data collection, through interviews and audiotape recording conducted by the primary researcher, aimed to understand the holistic experiences of these mothers. Colaizzi's method facilitated rigorous analysis, uncovering emergent themes and relationships, exploring the fundamental structure of their experiences. Steps involved reading transcripts, extracting significant statements, deriving formulated meanings, organizing them into thematic clusters, and integrating findings into a comprehensive description. The study's conclusions were validated through feedback from participants.

Results

Table 1. Demographic Characteristics of The Participants.

Variables	No of Participants	Percentage
Gender		
Female	12	100%
Age in years		
25-30	02	16.66%
31-35	06	50%
>36 years	4	33.33%
Qualifications		
Uneducated	03	25%
Primary	04	33.33%
Middle and above	05	41.66%

Table 1 reveals that a total of 12 study participants were interviewed in in this study. Looking at the gender characteristic, it revealed that all 12 (100%) of the participants were mothers (females). The age of study participants ranges from 26 years and above where 2 (16.66%) were age 26 to 30 years, 6 (50%) were 31-35 years and remaining 4(33.33%) were of age 36 years and above. Based on education qualification 3 (25%) were uneducated, 4 (33.33%) were primary and remaining 5 (41.66%) were middle and above education.

Qualitative Data Findings

Semi-structured interviews were conducted with each participant, allowing for a nuanced exploration of their experiences. Interviews were transcribed and subjected to thematic analysis to identify recurring patterns and themes. Qualitative analysis of the interview findings was categorized into four broad themes, as Emotional impact,

coping mechanism, impact on family dynamics and Financial Challenges faced by the parents of children having chronic kidney diseases.

Table2. Experienced Themes while mothers taking care of CKD children.

Theme	Sub Theme
Emotional Impact	➤ Initial Shock and Uncertainty Among Mothers
	➤ Confusion between hope and despair Among Mothers
	➤ Anxiety and panic among Mothers
Coping Mechanism	➤ Seeking Information and Education
	➤ Building Support Networks
Impact on Family Dynamics	➤ Worries about effects on family.
	➤ Changes in Relationships with Spouse/Partner
	➤ Sibling Dynamics and Adjustments
	➤ Extended Family and Social relationship
Financial Challenges	➤ Medical Expenses and Treatment Costs
	➤ Impact on Employment and Income

Theme 1: Emotional Impact: Mothers caring for children with chronic kidney diseases (CKD) grapple with a central theme of emotional impact, revealing a profound sense of concern, worry, and heightened emotional burden during in-depth interviews. Witnessing medical treatments, facing uncertainties about the future, and navigating the day-to-day realities of CKD contribute to a range of emotions, including anxiety, stress, and a deep sense of helplessness. This emotional toll extends beyond immediate health concerns, shaping various aspects of these mothers' lives and defining the overall narrative of their journey in caring for a child with chronic kidney diseases.

Sub-theme 1: Initial Shock and Uncertainty among Mothers: Mothers universally experienced disbelief and shock upon learning of their children's chronic kidney disease (CKD) diagnosis. This subtheme captures the initial emotional upheaval as they grappled with the stark reality, adapting to the mental and emotional challenge of navigating unfamiliar ground. Their lives were characterized by uncertainties, heightened awareness of time, and feelings of anxiety and apprehension associated with the passage of time.

One participant stated that “I was completely shocked by the news. The doctor detailed the consequences and complications of CKD, leaving me with numerous questions about how it would impact my child's future. It felt as though I had stepped into unexplored world, and a sense of disorientation overwhelmed me” (P3).

Another mother stated that “We are very worried about the child's illness, I mean that we cannot do anything else, there is only worry the whole time, and it is very difficult to take care of the child” (P6).

Subtheme 2: Confusion between hope and despair Among Mothers: This subtheme highlights

mothers of children with chronic kidney disease navigating a constant fluctuation between hope and despair. They grapple with disease-related challenges that may impact their children's future. While encouraging news about successful treatments, like kidney transplant surgery, brings a glimmer of hope, it is often tempered by the realization of potential complications, leading to a recurring sense of "care with despair" among participating mothers. This study identifies this fluctuation as a common thread among all mothers.

One participant stated that “I approach everything with a sense of despair. There seems to be no progress. I've heard that many individuals with CKD who undergo kidney transplants find relief from the suffering of the disease, offering a ray of hope for me. However, I've also witnessed a few children in this department who underwent kidney transplants only to experience rejection. This sight makes me wary, and I might lose hope once again” (P5).

One other participant stated “Every day feels like a balancing act between hope and despair. On one hand, I cling to the possibility of a better future for my child, especially when I hear about successful treatments like kidney transplants. But then, I've also seen cases where things didn't go as planned, and it's hard not to let doubt creep in. It's a constant emotional rollercoaster, and I find myself navigating through this confusion between hope and despair”(P9).

Subtheme 3: Anxiety and panic among Mothers: The emotional strain on mothers caring for children with chronic kidney disease extends to their mental health, marked by heightened stress, anxiety, and isolation. This is accentuated by the intricate link between the child's health and the mother's mental well-being, capturing moments of unease, restlessness, and panic during the care of children with CKD, particularly during hemodialysis and related treatments. The invasive nature of CKD treatments, with associated inconveniences and complications, contributes to mothers' anxiety and fear.

“Every moment I think about my child’s illness, so this creates a lot of depression. I become a mental patient and almost got sick” (P5).

Another Mother stated that: “Every time my son is hooked up to dialysis machine and I see his blood being drawn from his body, I become genuinely scared, especially on days when his blood pressure drops. In those moments, it feels like I'm on the verge of losing my son. The anxiety lingers even when I try to sleep at night, and I often wake up overwhelmed with distress” (P1).

Theme 2: Coping Mechanisms

Subtheme 1: Seeking Information and Education: A recurring theme in parents' experiences was their dedicated pursuit of knowledge, emphasized by most participants. Recognizing the importance of effectively managing their child's condition, parents actively sought to raise awareness and acquire in-depth knowledge. They utilized available resources to gain essential insights into managing their child's health.

In this context, one of the parents articulated the following sentiments:

“Whenever healthcare professionals visit our room to attend to my child, I attentively listen to their explanations regarding the medications and serums being administered. This allows me to gather valuable information about these treatments” (P11).

This was corroborated by the statements of one parent, who articulated her experience in this context as follows:

“I make a conscious effort to engage in extensive conversations with individuals who have a child facing kidney problems. I communicate with them to understand their perspectives and insights. I collect information and gather resources from their experiences, swiftly implementing actions that could positively impact my child's health status” (P2).

Conversely, parents were distressed by the absence of specific education and information on how to manage the health of their children.

Stated by another participant:

“We lack knowledge about the purpose of these medications, and we are uncertain about where to purchase them and the correct administration procedures” (P3).

Subtheme 2: Building Support Networks: In the broader context of mothers raising children with chronic kidney diseases (CKD), the subtheme of establishing support networks emerges as crucial. Mothers actively worked to create strong networks by connecting with fellow parents, forming a community for exchanging insights and emotional support. These networks were invaluable, providing understanding and solidarity, essential for navigating the intricate challenges of CKD.

Several participants stated in favor of health care professional especially nurses as stated by a mother:

“The nurses here are incredibly kind. They provide detailed explanations to me, emphasizing the importance of frequent hand washing for both myself and my son. They advise wearing a mask whenever entering the hall and stress the necessity for my son to avoid going outside at all during the fall and winter seasons” (P5).

Similarly, one other participant stated that:

“The nurses here offer considerable comfort. Whenever tears came, they would enter and discuss other patients' situations with me, providing words of encouragement” (P9).

Also, family support was mentioned by few participants and that admired that family role and support is extremely important and a source of relief as stated by one mother:

“Whenever I require assistance, I consistently reach out to my mom for help. For instance, she comes over to lend a hand with household chores” (P5).

Another mother stated that:

“When a child is on dialysis, the mother's life seems to fade away, and there is a lack of attention to her needs. My sibling dismissed it as mere that I am doing drama on my part” (P6).

One participant also mentioned lack of support from

doctors and stated that:

“Doctors also take long time in responding and give time according to their own limited schedule. Further, not only doctors but also medicine, tests, etc., and hospitalization furthermore is very challenging” (P1).

Theme 3: Impact on Family Dynamics

Subtheme 1: Worries about effects on family:

The challenges faced by unwell children can impact the entire family, requiring consistent care and monitoring. The mothers' regular presence in the hemodialysis department three days a week, coupled with their absence at home, can lead to family disarray, affecting the physical, psychological, and educational well-being of other children in the family.

Stated by one participant:

“My eldest son is currently attending high school, and due to the demands of the one-year hemodialysis, I've been unable to dedicate time to him. As a consequence, my oldest son is grappling with academic challenges and experiencing feelings of depression” (P1).

Participant No. 4, who has two other children and lives 3 hours away from the hemodialysis center stated:

“For three days a week, from morning until evening, I leave my children alone at home. I am constantly concerned about their eating habits and activities. This situation has made my little daughter anxious” (P4).

The distance from the hemodialysis center and the expenses related to frequent travels to the hospital, and disruptions to parents' employment can place a substantial financial strain on families. All twelve participants conveyed significant apprehensions regarding their household situations and the potential impact on their children.

Subtheme 2: Changes in Relationships with Spouse/Partner:

Spousal relationships experienced changes in dynamics in response to the challenges presented by CKD. This subtheme delves into the shifting roles and communication patterns between mothers and their partners.

One Participant stated that:

“My husband has become very irritable. When he is also worried all the time. He fights at home. Sometimes in anger he also hits my children. Right, sometimes he even raises his hand on me in anger. Now this is mental, there is a headache, we feel strange that our home conditions are not good either” (P10).

Subtheme 3: Sibling Dynamics and Adjustments

The influence on siblings became a poignant element of family dynamics. Mothers deliberated on the

adaptations siblings underwent and the tactics employed to cultivate understanding and support among all family members.

One Participant stated that:

“The influence of my child's CKD on the dynamics among siblings has been significant. In the beginning, my other children experienced confusion and fear as they didn't completely grasp the implications of their sibling's condition, leading to emotional challenges. However, as time passed, we initiated open conversations, and they became more actively involved in the caregiving process” (P4).

Subtheme 4: Extended Family and Social relationship: Extended family involvement, while occasionally helpful, also contributes to challenges in the overall family support structure. Mothers of children undergoing hemodialysis face a social burden, missing typical social interactions due to time constraints and commitment to the treatment schedule. The constant presence during dialysis and commitment to extended care limit their engagement in regular social activities, creating barriers to forming connections with family and friends.

One mother participant stated that:

“My relationships with other relatives are strained. Visiting them is challenging, and I can't find time for my other children at home. I am unable to attend events, whether they be moments of sorrow or joy. Most significantly, I struggle to allocate time for my husband. Life has become incredibly challenging, and my connections with everyone have diminished since my daughter fell ill” (P9).

Theme 4: Financial Challenges

Subtheme 1: Medical Expenses and Treatment Costs: Managing substantial medical costs and treatment expenses for children with chronic kidney disease (CKD) poses a financial burden for mothers, impacting their ability to provide comprehensive care. The intricate network of healthcare expenses, ranging from tests to potential surgeries and transplants, contributes to continuous financial challenges. These economic pressures influence decisions related to work, lifestyle, and long-term financial planning, testing the resilience of mothers as they seek the best care for their children amid CKD's chronic nature.

One participant stated that:

“The financial burden of my child's CKD has been overwhelming, especially with the constant medical appointments, medications, and treatment costs. It's a never-ending cycle of expenses that we hadn't anticipated” (P7).

Similarly, another participant stated that:

“The impact of medical expenses is profound, forcing

us to make sacrifices in various aspects of our lives just to meet the costs of my child's treatment. It serves as a harsh reality check, highlighting that managing CKD requires not only emotional strength but also financial resilience” (P4).

Subtheme 2: Impact on Employment and Income: Balancing caregiving responsibilities with workplace demands becomes challenging for mothers of children with chronic kidney disease (CKD), impacting employment and income. The dilemma of prioritizing a child's health over financial stability is a persistent stressor, leading to decisions like part-time work or flexible schedules. Job loss or reduced working hours are harsh realities for some mothers, affecting family budgeting and the ability to provide a stable environment for the child. The impact on employment and income is a poignant subtheme in the intricate narrative of mothers navigating CKD challenges.

One participant stated that:

“We have to manage these jobs and sometimes we ask our neighbors for cooking. Their father takes care of them, sometimes he goes to work and sometimes he does not, and we have to arrange this all by selling something from our assets. It is very difficult. Life is suffering hard.” (P4).

Similarly, another participant stated that:

“Juggling between work and caregiving has become exceedingly difficult. There are days when I must skip work to address my child's health requirements, leading to an impact on our family income. It's a challenging decision between maintaining financial stability and being present for my child” (P2).

Discussion

The present study was conducted to explore the “experience of mothers having children with chronic kidney diseases”. For this purpose, interviews from 12 mothers were conducted who were looking after their children during hemodialysis and other treatments. After the data collection, thematic analysis was applied for analysis. Four major themes were extracted which were; Emotional Impact on mothers and family, Coping Mechanism among mothers having children with CKD, Impact on Family Dynamics and Financial Challenges faced by the mothers and families of children with CKD.

The narratives shared by these mothers' portrayed lives filled with uncertainties, prompting them to adjust to the mental and emotional demands of navigating uncharted territory. Their daily existence was marked by an increased consciousness of time, accompanied by emotions of anxiety and apprehension associated with the ticking of the clock.

The results align with a previous study that uncovered the participating mothers were “submerged in a sea of psychological tension.” The perception that a child's life

relies on consistent hemodialysis, coupled with the invasive, time-consuming nature of the procedure and its potential complications or inconveniences, imposed significant psychological pressure (16). The results are also consistent with outcomes from other studies where it was observed that parents of children with chronic kidney diseases experienced significant stress and emotional pressure (14).

Moreover, another past study found that mothers of children with chronic kidney disease face mental health challenges. They encounter stress, fatigue, disruptions in peer relationships and bonding, financial concerns, limitations in daily life activities, and difficulties in fulfilling routine responsibilities (17).

The current study results also found that understanding of the prognosis can at times evoke a sense of encountering an overwhelming obstacle; the term "care with despair" was a frequently used expression among the mothers involved in the study. Along with hope, the awareness of potential complications, such as the risk of kidney transplant rejection, resulting in a feeling of hopelessness regarding their children's prospects. This study identified this oscillation between hope and despair as a prevailing theme among all the mothers.

A previous study also found similar findings where many participants highlighted the uncertain prognosis of this disease with an unknown origin. The lack of clarity regarding the future course of the disease and uncertainties about the child's life can be disorienting for parents, causing them to lose their composure (18). Research conducted by Bally et al. revealed that parents of children facing life-threatening illnesses grappled with profound uncertainty, specifically concerning their concerns about their child's future (19).

This study also found mothers' experiences of unease, restlessness, nervousness, fear, and panic while tending to children with CKD undergoing hemodialysis and other treatments. The invasive aspects of CKD treatments, like Hemodialysis, introduce various inconveniences and complications. These additional challenges intensify feelings of anxiety and fear among mothers.

Consistent with this study, a previous study found the encounters of anxiety, restlessness, nervousness, fear, and panic faced by mothers of children undergoing hemodialysis, reflecting their experiences (16).

Another similar findings revealed by a past study where mothers are profoundly affected by the distressing emotions of anxiety and panic stemming from the looming possibility of imminent death (20).

The current study found that through various support systems such as, health care providers, family members' support etc, the mothers discovered comfort, shared effective coping strategies, and gained collective strength, bolstering them in their journey of caring for children with chronic kidney diseases. Mothers underscored the significance of cultivating robust support networks, involving healthcare professionals, family, and friends, emphasizing that the quality of these networks played a

crucial role in alleviating the challenges associated with raising a child with CKD.

Congruently in a previous research study, also parents discussed the guidance and education they received from nurses, doctors, and other resources, enhancing their knowledge. Consequently, this empowered them to offer high-quality care to their children with a greater sense of peace of mind (21).

The systematic review offers a succinct summary of qualitative studies on parents caring for children with CKD, providing insights applicable to the challenges of parenting technologically dependent or chronically ill children. The findings can inform the development and evaluation of support strategies by general practitioners, specialized teams, and family members for parents of children with CKD (22).

Furthermore, this study revealed that the mothers' regular presence in the hemodialysis department three days a week, coupled with their absence at home, can lead to family disarray. This, in turn, may affect the physical, psychological, and educational well-being of the other children in the family.

Consistent with the current study findings, a previous study found that the chronic illness of a family member typically results in a substantial disruption to the structure and functioning of family systems (23). According to another study findings, it was crucial for every family member that the organization of daily life and the care of the child revolved around reserves of energy. The welfare of the child served as an indicator of the well-being of the entire family (24).

Moreover, the current study also revealed that the Spousal relationships experienced changes in dynamics in response to the challenges presented by CKD. Also, the influence on siblings became a poignant element of family dynamics.

Supported findings are revealed by the past studies where Caregiver parents, particularly spouses, often experience a greater sense of burden compared to other caregivers, as extended caregiving can negatively impact marital satisfaction (25). Accordingly another past research revealed that chronic illnesses like CKD can result in a loss of control and heightened dependence, negatively impacting family members and hindering their ability to function effectively, including neglecting personal care (26).

The disease left its mark and changes to daily life caused anxiety, especially for siblings. Family members feel vulnerable and concerned and need attention, support and care. Limitations in everyday life cause a dilemma, and the well-being of one family member has an impact on the well-being of the family as a whole (Agerskov et al., 2019).

Another past study found that mothers experience exhaustion from commuting to the hospital for hemodialysis therapy, and their children frequently face hospitalization. Additionally, it is mentioned that caregivers, especially mothers, suffer from fatigue due to insufficient time for rest, which subsequently has adverse effects on their other children (27).

The study indicates that mothers caring for children undergoing hemodialysis face a social burden due to time constraints and dedication to the treatment schedule. This commitment hinders their participation in typical social interactions, as they prioritize being present for their children during hemodialysis sessions. This dedication creates obstacles for mothers to engage in regular social activities and build connections with others. The research aligns with previous findings, where participants limited recreational activities and family outings due to their child's compromised immune system, making social events challenging. The mother's crucial role in extended care further emphasizes the difficulties in forming connections with family and friends (23). Likewise, findings from another previous study indicated that participants expressed the necessity to curtail their social interactions owing to their child's specific dietary requirements and complications related to the disease (11).

The study highlights the persistent financial strain on families managing chronic kidney disease (CKD), encompassing extensive medical costs. Navigating healthcare expenses, including tests and surgeries, contributes to the burden. Mothers frequently take work breaks for medical needs, affecting income and careers. Prioritizing a child's health over financial stability is an ongoing stressor. A previous study indicated mothers of children with CKD faced social, financial, and psychological challenges, with high rates of depressive symptoms, anxiety, and financial problems experienced by the majority of mothers (Khanna et al., 2015).

Another study found that providing mothers with financial and emotional support and assisting them in locating support resources can all aid the mothers' ability to adjust to the chronic disease of their kid. The ability to recognize and remove obstacles to adaptation is another way in which mothers can improve their ability to deal with the chronic illness of their child (Khorsandi et al., 2020).

Another past study also presented the financial challenges such as the distance from the hemodialysis center, along with the expenses linked to frequent hospital travels, medication costs, and disruptions to parents' work, can place a significant financial strain on families. All participants, without exception, voiced grave concerns about the impact of their household financial situation on their children (16).

Conclusion

The study concludes that mothers caring for children with chronic renal failure undergoing hemodialysis face a range of challenges. Emotional impacts, coping mechanisms, shifts in family dynamics, and financial challenges were identified as key themes. The initial shock and uncertainty, combined with the delicate balance between hope and despair, highlight the profound emotional toll on these mothers. Coping mechanisms, such as seeking information and building support networks, play a crucial role in navigating challenges. Family dynamics are affected in various ways, including

concerns about broader family effects, changes in relationships, adjustments among siblings, and considerations of extended family and social relationships. Financial challenges, including medical expenses and treatment costs, add significant stress, impacting employment and income. The findings emphasize the complex emotional, social, and financial implications for mothers of children undergoing hemodialysis, highlighting the need for targeted support strategies and interventions to enhance the well-being of both the child and the family.

References

- Romagnani P, Remuzzi G, Glasscock R, Levin A, Jager KJ, Tonelli M, et al. Chronic kidney disease. *Nature reviews Disease primers*. 2017;3(1):1-24.
- Carney EF. The impact of chronic kidney disease on global health. *Nature Reviews Nephrology*. 2020;16(5):251-2.
- Ahn S-Y, Moxey-Mims M. CKD in children: the importance of a national epidemiologic study. *American Journal of Kidney Diseases*. 2018;72(5):628-30.
- Becherucci F, Roperto RM, Materassi M, Romagnani P. Chronic kidney disease in children. *Clinical kidney journal*. 2016;9(4):583-91.
- Ambarsari CG, Tambunan T, Pardede SO, FH FR, Kadaristiana A. Role of dipstick albuminuria in progression of paediatric chronic kidney disease. *JPMA The Journal of the Pakistan Medical Association*. 2021;71(2):S103-S6.
- Thorsteinsdottir B, Ramar P, Hickson LJ, Reinalda MS, Albright RC, Tilburt JC, et al. Care of the dialysis patient: Primary provider involvement and resource utilization patterns-a cohort study. *BMC nephrology*. 2017;18(1):1-8.
- Kaspar C, Bholah R, Bunchman T. A review of pediatric chronic kidney disease. *Blood purification*. 2016;41(1-3):211-7.
- Quigley R. Chronic kidney disease: highlights for the general pediatrician. *International journal of pediatrics*. 2012;2012.
- Caskey FJ, Morton RL. Optimising care for children with kidney disease. *The Lancet*. 2017;389(10084):2084-6.
- Levy Erez D, Krause I, Dagan A, Cleper R, Falush Y, Davidovits M. Impact of pediatric chronic dialysis on long-term patient outcome: single center study. *International journal of nephrology*. 2016;2016.
- Khorsandi F, Parizad N, Feizi A, Hemmati MaslakPak M. How do parents deal with their children's chronic kidney disease? A qualitative study for identifying factors related to parent's adaptation. *BMC nephrology*. 2020;21(1):1-14.
- Darwish MM, Hassan SH, Taha SF, Abd El-Megeed HS, Ismail TA-AM. Family impact and economic burden among caregivers of children with chronic kidney disease in Assiut, Egypt. *Journal of the Egyptian Public Health Association*. 2020;95:1-8.
- Wong H, Mylrea K, Feber J, Drukker A, Filler G. Prevalence of complications in children with chronic kidney disease according to KDOQI. *Kidney international*. 2006;70(3):585-90.
- Geense W, Van Gaal B, Knoll J, Cornelissen E, van Achterberg T. The support needs of parents having a child with a chronic kidney disease: a focus group study. *Child: care, health and development*. 2017;43(6):831-8.
- Bignall OR, Goldstein SL. Childhood CKD affects the entire family. *American Journal of Kidney Diseases*. 2015;65(3):367-8.
- Pourghaznein T, Heydari A, Manzari Z, ValizadehZare N. "Immersion in an ocean of psychological tension:" The voices of mothers with children undergoing hemodialysis. *Iranian Journal of Nursing and Midwifery Research*. 2018;23(4):253.

- Saeed HS, Sinjari HY. Assessment of hemodialysis efficacy in patients with end-stage renal failure in the Erbil hemodialysis center. *Medical Journal of Babylon*. 2018;15(4):276-80.
- Hemmati MaslakPak M, Parizad N, Feizi A, Khorsandi F. "Will My Child's Illness be Cured?" Challenge of Parents whose Children Admitted to Nephrology Department with Chronic Kidney Disease: A Qualitative Study. *Health Education and Health Promotion*. 2022;10(3):547-53.
- Bally JM, Smith NR, Holtslander L, Duncan V, Hodgson-Viden H, Mpofu C, et al. A metasynthesis: uncovering what is known about the experiences of families with children who have life-limiting and life-threatening illnesses. *Journal of pediatric nursing*. 2018;38:88-98.
- Verberne LM, Kars MC, Schouten-van Meeteren AY, van den Bergh EM, Bosman DK, Colenbrander DA, et al. Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study. *European journal of pediatrics*. 2019;178:1075-85.
- Khorsandi F, Parizad N, Feizi A, MaslakPak M. How do parents deal with their children's chronic kidney disease? A qualitative study. 2020.
- Ong ZH, Ng CH, Tok PL, Kiew MJX, Huso Y, Shorey S, et al. Sources of distress experienced by parents of children with chronic kidney disease on dialysis: a qualitative systematic review. *Journal of Pediatric Nursing*. 2021;57:11-7.
- Oyegbile YO, Brysiewicz P. Family caregiver's experiences of providing care to patients with End-Stage renal disease in South-West Nigeria. *Journal of Clinical Nursing*. 2017;26(17-18):2624-32.
- Agerskov H, Thiesson HC, Pedersen BD. Everyday life experiences in families with a child with kidney disease. *Journal of renal care*. 2019;45(4):205-11.
- Hoang VL, Green T, Bonner A. Informal caregivers' experiences of caring for people receiving dialysis: A mixed-methods systematic review. *Journal of renal care*. 2018;44(2):82-95.
- Kruszecka-Krówka A, Smoleń E, Cepuch G, Piskorz-Ogórek K, Perek M, Gniadek A. Determinants of parental satisfaction with nursing care in paediatric wards—A preliminary report. *International journal of environmental research and public health*. 2019;16(10):1774.
- House TR, Wightman A, Rosenberg AR, Sayre G, Abdel-Kader K, Wong SP. Challenges to shared decision making about treatment of advanced CKD: a qualitative study of patients and clinicians. *American Journal of Kidney Diseases*. 2022;79(5):657-66. e1.