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CAREGIVING CHALLENGES IN HOME-BASED HEMODIALYSIS: A QUALITATIVE ANALYSIS

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Abstract

Background: *Chronic kidney disease (CKD) is a growing health concern in Pakistan, with prevalence rates ranging from 12.5% to 29.9%. Home caregivers of patients undergoing hemodialysis face significant physical, emotional, and informational burdens, which affect both their well-being and the quality of care provided.*

Objective: *To explore the challenges faced by home caregivers attending to hemodialysis patients.*

Method: *A qualitative descriptive design was used. Twelve primary caregivers with direct caregiving experience were selected through purposive sampling. Data were collected via in-depth interviews, transcribed, and analyzed using thematic analysis.*

Results: *Five major themes emerged:*

1. ***Physical and daily caregiving challenges*** *(e.g., care fatigue, lifestyle changes)*
2. ***Lack of knowledge and information*** *(e.g., inadequate medication management, need for education)*
3. ***Emotional and psychological stress*** *(e.g., anxiety, feeling overwhelmed)*
4. ***Impact on family dynamics*** *(e.g., disrupted leisure time, shifting responsibilities)*
5. ***Financial strain*** *(e.g., treatment costs, job disturbances)*

Conclusion: *Home caregivers of hemodialysis patients face multifaceted challenges that significantly affect their physical, emotional, and financial well-being. Addressing these needs through education, support systems, and policy-level interventions is essential to improve both caregiver and patient outcomes.*

INTRODUCTION

Individuals with chronic kidney disease (CKD) have frequent interactions with the health care system due to the presence of multiple comorbidities and complications of CKD including diabetes, anemia, and extremely high rates of cardiovascular disease and mortality. In addition, people with CKD have poor quality of life and low functional status that worsens with kidney disease progression and is lowest in individuals with kidney failure on dialysis (Sass et al., 2020).It might be difficult for individuals with renal failure to get personalized hemodialysis (HD) therapy in clinical settings. Individualization is the practice of providing care that is tailored to each person's unique situation, values, and preferences. (Sass et al., 2020). In India, the prevalence of chronic kidney disease (CKD) has been gradually rising. About 55,000 individuals are thought to be receiving dialysis in India, and the number of dialysis patients is increasing by 10% to 20% a year.(Nimah, Nursalam, Wahyudi, & Mariyanti, 2024).

When the kidneys are unable to eliminate waste and extra fluid from the body, dialysis is recommended. Hemodialysis (HD) and peritoneal dialysis (PD) are the two forms of dialysis. PD is more frequently performed at home and involves a cycle in which a dialysate fluid is inserted into the patient's peritoneal cavity via a catheter and then extracted. HD can be performed at home or at a facility, with the patient's blood passing through a dialyzer filter (RANI & KAMALA, 2020). Their lifestyle is drastically altered by hemodialysis. Patients' and their caregivers' regular lives are disrupted by hemodialysis since it lowers their energy levels and, due to the frequent requirement for dialysis, inhibits their capacity to work and carry out daily tasks (Jafari, Kour, Giebel, Omisore, & Prasad, 2020).

Dialysis is used by 71% of the 678,000 patients with end-stage renal failure in the United States. The disorder's annual growth rate in Iran is over 12%, which is greater than the global average. (Jafari et al., 2020). The person who is most directly involved in providing care and assisting the patient in managing and coping with their condition during treatment is known as the carer. About 69% of all kidney replacement therapy and 89% of all dialysis are haemodialysis (HD), making it the most used type of kidney replacement therapy worldwide. The prevalence of CKD in Pakistani adults was 21.2% overall. High-quality research indicate that the highest prevalence of chronic kidney disease (CKD) in Pakistan was 29.9%, while the lowest prevalence was 12.5%. (Nimah et al., 2024).

Chronic renal disease has a high prevalence of morbidity and mortality and is a severe and growing health issue. According to data released in 2016, there are an estimated 752.7 million individuals with chronic kidney disease globally, with approximately 3 million of them undergoing dialysis treatment. There were 25,000 haemodialysis (HD) patients in Iran in 2013(Baghcheghi & Koohestani, 2021).

Due to the availability of formal or paid careers, the career burden is comparatively lower in industrialized nations like the US, UK, and Australia. Just 40% of ESRD patients in Pakistan are thought to have access to dialysis, and 67% of them are dialyzed, which puts a lifetime burden on them and continuously stresses out their careers. Assessing the caregiving burden of dialysis patients and its effects on their quality of life was the goal of the current study (Shah, Ali, Finlay, & Salek, 2021).

Additionally, these careers deal with a rigid therapy regimen that interferes with their everyday lives and ongoing concerns about potential complications that patients may acquire after treatment. By helping with therapeutic procedures, overseeing medical supplies, and continuously sterilising objects and the home environment, PD carers envision even more demanding actions. (Hovadick, Jardim, Paúl, Pagano, Reis, & Torres, 2021).

Dialysis is used by 2.5 million individuals worldwide. Compared to in-center HD, home haemodialysis (HD) can provide patients with greater autonomy and flexibility, as well as improved health, quality of life, and survival. Nevertheless, home HD is underutilised, accounting for fewer than 5% of dialysis modalities in North America, Europe, South America, and Asia, and only 18% and 12% of dialysis modalities used in Australia and New Zealand, respectively. Additionally, home HD is thought to be an economical way to satisfy the growing demand for renal replacement therapy worldwide (Hanson et al., 2020).

The family caregivers of patients on hemodialysis (HD) and peritoneal dialysis (PD) typically experience higher burden than the general population because of the nature of tasks these caregivers need to carry out as a part of homecare. This fact influences both the caregivers' quality of life and the quality of their scare toward the patient Different articles results have mostly explored the challenges and caring experience for the caregivers with patients having Hemodialysis which are directly affect the quality of life. Accepting the practice of caregivers challenges are important for knowing how best to support and mange with them in the context of home medical care for CKD patients with hemodialysis (Hovadick et al., 2021).

These caregivers also experience constant worry due to complications that patients may develop during treatment and face an inflexible therapy routine that affects their daily life. PD caregivers envisage even more stressful activities by assisting in therapeutic procedures, managing the medical supplies and constantly sterilizing the materials and home environment (Andreoli & Totoli, 2020). All these activities, in addition to their personal demands, leave them in a state of distress and excessive burden. Consequently, caregivers of patients undergoing HD have poorer QOL than the general population along with significant burden levels (Martin, Burton, & Wyld, 2022).

However, the latter group has major medical responsibilities and they play the integral role of the main care provider. Specific tasks of their role include special diet preparation, medication control, patient personal care (e.g., oral hygiene and bathing), and special attention with patients' vascular access. Such heavy workload and high levels of burden adversely affects the well-being of caregivers, making them more susceptible to depression, anxiety, and other medical conditions. This eventually leads to increased public and private healthcare expenditures. Furthermore, it impacts the care provided to the patients and consequently, the success of their treatment (Cloutier, Manceur, Guerin, Aigbogun, Oberdhan, & Gauthier-Loiselle, 2020).

Long-term caregiving efforts also affect family caregivers' psychological health. Ambivalence in life status, mental and psychological problems, mental exhaustion, lack of basic necessities, spiritual problems, adaptations and emotions that result from caring, and coping mechanisms are some of the themes associated with psychological states. Significant stress in this study is caused by a number of factors, including the chronic nature of the disease, the patients' physical condition, medications, food, challenges after hemodialysis, and the increasing nature of the care. A similar Iranian study found that caregivers of hemodialysis patients experienced high levels of anxiety. It was believed that because being a primary caregiver was a difficult role, it interfered with family health (Salehitali, Ahmadi, Dehkordi, Noorian, Fereidooni-Moghadam, & Zarea, 2018).

Furthermore, the treatment of patients with chronic kidney disease (CKD) by family caregivers may result in problems with social connections. A previous study identified a number of issues, including family or everyday life, collaborative care, and social disturbance. As this study has demonstrated, the isolation of the patient and caregiver as a result of the sickness and dialysis, as well as the reduction of the caregiver's social connections, led to additional social problems. Several social relations topics were discovered to be impacted in previous studies by (Abebe et al., 2022) (Nkuranyabahizi et al., 2021).

A decrease in household income and fewer opportunities for obtaining additional revenue also result in indirect costs (Northall, Chang, Hatcher, & Nicholls, 2020). Another study found that hemodialysis patients put a heavy financial burden on their caregivers. This highlights the necessity of laws and initiatives that provide patients and caregivers with social and financial support while reducing the burden on at-home caregivers (Solaimanimoghaddam, Beydokhti, & Firouzkohi, 2024).

The findings of these various themes were derived from a study on stroke patients' family caregivers, which revealed a significant impact on physical capacity as a result of the patients' long-term care. This review found that fatigue was the main factor contributing to family caregivers' physical capability issues (Nimah et al., 2024). A previous study found that caregivers of hemodialysis patients encounter a number of challenges due to their ignorance of different facets of caregiving, including as medication administration, personal cleanliness, dietary needs, and home care. These kinds of deficits can lead to stress and overwork among caregivers, which can lead to subpar patient care and a drop in caregiver wellbeing. Participants frequently struggle to comprehend drug side effects, quantities, and when to administer it. This can result in non-compliance or medication errors, which worsen the patient's condition. Recent research emphasizes the importance of thorough training and clear, direct communication between healthcare providers and caregivers regarding medication regimens, especially for patients with chronic kidney disease (CKD) (Nkuranyabahizi et al., 2021).

Objective:
To explore the challenges of caregivers for attending hemodialysis patients at home

MATERIAL AND METHODS

Study Design:

A qualitative descriptive research study design was used to explore the challenges that primary caregivers encounter when providing hemodialysis patients at home

Study Setting and Population:

The research was carried out at the dialysis and outpatient departments of Jinnah Hospital and General Hospital located in Lahore, Pakistan. Those who had been providing care for at least six months before to the study, were willing to participate, and were registered as the primary family caregiver.

Data Collection:

The study participants were contacted when they went to the dialysis and outpatient departments for hemodialysis and follow-up visits. Approaches were made to the participants in the dialysis unit and outpatient departments. The primary caregivers were questioned sparingly in order to incorporate them in accordance with the inclusion and exclusion criteria. In the study, only participants who met the inclusion criteria were included. The participants received a thorough explanation of the study's goals and objectives. The participants received assurances that their participation in the study is entirely voluntary and that they will not get any financial rewards. The participants gave their consent, and in order to maintain secrecy, the data was gathered in a different room. Audio recordings and interviews were used to gather data. The primary researcher served as a source of data collection herself.

Data Analysis:

Every study participant had an in-depth interview conducted in order to gather data. Through in-person interviews, the researcher was able to describe the difficulties faced by main caregivers of CKD patients receiving hemodialysis. Through these interviews, a more comprehensive understanding of the participant's overall experiences was obtained.

Using Colaizzi's method, the analysis is thorough and reliable, guaranteeing the validity and dependability of its findings. By exposing emerging themes and their intricate connections, it enabled researchers to delve into the underlying framework of an encounter. The following steps were taken in order to extract, organize, and analyze the data using Colaizzi's data analysis technique:

1. To get a basic idea of the entire content, each transcript was read in detail
2. Key quotes from transcripts that are relevant to the phenomenon being studied were extracted.
3. Important statements were used to formulate meanings.
4. The arrangement of developed meanings into theme clusters.
5. Including the results in a comprehensive explanation.
6. An explanation of the phenomenon's basic structure.
7. Verification of the study participants' conclusions

Results:

Table 1: Demographic Characteristics of the participants

Participant Number	Age in Years	Gender	Marital status	Occupation	Education	Length of care	Caregiver Relationship with patient
1	35	Female	Married	Housewife	High School	2 years	Wife
2	55	Male	Married	Worker	Middle School	1 year	Father
3	50	Female	Married	Housewife	Primary	4 years	Wife

4	28	Female	Unmarried	Teacher	Bachelors	14 months	Daughter
5	25	Female	Unmarried	No Job	High School	3 years	Daughter
6	56	Male	Married	Retired	Bachelors	5 years	Husband
7	54	Female	Married	Housewife	Illiterate	2 years	Wife
8	25	Female	Unmarried	Student	Bachelors	1 year	Sister
9	25	Male	Unmarried	Student	Bachelors	2 years	Son
10	29	Male	Married	Self-job	High School	5 years	Son
11	48	Female	Married	Teacher	Bachelors	3 years	Mother
12	52	Female	Married	Housewife	Illiterate	4 years	Wife

The results, demographics, and patient-caregiver relationships of 12 caregivers are displayed in Table 1. The participants are primarily female, with ages ranging from 25 to 56. While there are unmarried people in the category as well, marriage makes up the bulk of the population. They are housewives, laborers, teachers, retirees, students, and jobless people, among other jobs. The caregivers' educational backgrounds range from complete illiteracy to possessing a bachelor's degree. Caregiving tenure varies from one year to five years, corresponding to different levels of experience. The majority of the caregivers are spouses, parents, daughters, and other close family members of the patients. These caregivers work in long-term care, especially in parent-child or spouse partnerships

4.2. Qualitative Data Findings:

Each participant had a semi-structured interview, which allowed for a thorough examination of their caring challenges. To find reoccurring themes and patterns, the transcripts of the interviews were thematically analyzed. The results of the qualitative analysis of the interview questions were divided into five main categories: physical and biological day-to-day challenges; lack of knowledge and information; emotional and psychological difficulties; impact on family dynamics and financial difficulties faced by study participants who were caring for hemodialysis patients.

Table2. Experienced Challenges Themes while taking care for hemodialysis patients

Theme	Sub-Theme
Physical & Biological day to day life Challenges	➢ Compulsive Care Compliance ➢ Conflicts Between Leisure Time And Caregiving ➢ Care Fatigue ➢ Lifestyle Change
Lack of Knowledge and Information Challenges	➢ Inadequate medication management knowledge ➢ Lack of knowledge about the complexities ➢ Seeking Information and Education
Emotional and Psychological Impact	➢ Initial Shock and Uncertainty ➢ Feelings of being overwhelmed ➢ Feeling of distress and anxiety
Impact on Family Dynamics	➢ Worries about effects on family ➢ Changes in Relationships with family members ➢ Extended Family and Social relationship ➢ Lack of Social Support
Financial Challenges	➢ Medical Expenses and Treatment Costs ➢ Impact on Employment and Income

4.2.1. Theme 1: Physical and Biological Day to Day Life Challenges:

The equilibrium between everyday chores and care providing tasks is upset when a patient receiving hemodialysis is given an excessive workload. Most caregivers believed that their daily activities and family obligations were being hampered by the caregiving load. The first main theme that emerged inductively from participant replies is the struggle of day-to-day living. This theme arose from participant comments that elucidated characteristics pertaining to the biological and physical effects of hemodialysis (HD) on caretakers. The theme is divided into four main sub-themes: compulsive care compliance, Conflicts between Leisure Time and Caregiving, Care Fatigue and Lifestyle Change

4.2.1.1. Sub-theme 1: Compulsive Care Compliance:

Dialysis patients are extremely dependent on their caregivers because of the instability that results from their physiological circumstances and the necessity of being frequently referred to treatment centers for hemodialysis. There are instances where this dependence is so great that the caretakers are unable to even leave their patients alone. As a result, the caregivers' lives are constrained and they must modify their schedules to accommodate the needs of their patients. Participants in this study identified several barriers, including an excessive dedication to caregiving responsibilities between daily life and caregiving, care provision, restrictions on future decision-making, and ignoring oneself for the benefit of the patient.

A woman caregiver responded, *"My husband needs my attention all the time, therefore I don't have enough time to attend to my family's needs"* (P1)

Another participant stated that:

"I'll save the chores at home for another day if my mom isn't feeling good. Well, let them. I stored everything" (P4).

"We now play different roles. In a way, I am a mother and my mother is a child at home, but things were better in the past. While we have our mother, we are without certain aspects of ourselves. We're not rising or falling; for some reason, we're just standing still. The passage of time has ended" (P10).

4.2.1.2. SUB-THEME 2: Conflicts between Leisure Time and Caregiving:

Family caregivers cannot spend their free time as they would want due to disputes in caregiving and patients' unpredictable circumstances. The study's participants discussed problems like scheduling conflicts for leisure, traveling, and taking part in events like parties, cosmetic lessons, sports, and religious rites.

Interestingly, participants said the following:

"Most of my hobbies have been overtaken by caregiving. I am unable to travel overseas, for instance, or even attend a friend's wedding or celebration. In actuality, they don't have the patience to tolerate these lengthy events. We would rather consider their comfort as a result, and we do not go" (P5).

4.2.1.4. Subtheme 4: Lifestyle Change:

The participants' new and difficult way of life is a lifestyle shift brought on by their extremely demanding patient care position. Among the lifestyle adjustments that were noted were being cautious about their health and changing their views or viewpoint on end-stage renal illness.

A participant explained in the following manner:

"The caregiving obligation for HD patients necessitates a change in lifestyle. A person would stop thinking about himself when he got into this circumstance. For example, I don't eat enough or frequently enough, I don't know how I dress, and I don't think about or have time to maintain my cleanliness" (P2)

4.2.2. Theme 2: Inadequate Knowledge and Information:

The participants acknowledged that lacking information and knowledge made it difficult to take on new practical duties and obligations. These duties included helping with personal care needs, controlling the amount of food and liquids needed, administering medication, and doing other home chores that left caregivers feeling overburdened. The three main components of this theme that address these problems are: inadequate knowledge of medication management; inadequate understanding of the complexity; and seeking out information and instruction regarding renal care.

4.2.2.1. Subtheme 1: Inadequate Medication Management Knowledge:

According to the participants, properly ordering, gathering, organizing, storing, and administering drugs is a difficult process that requires both mental and physical fatigue. Caregivers faced intense accountability and practical challenges as a result of these responsibilities, which greatly increased their burden. For example, they were worried that they could forget to provide their loved one's prescription, which could have a detrimental effect on their health.

"His numerous prescriptions for renal, diabetic, and heart problems make it extremely difficult to give and manage them. I have to make notes for myself to ensure that I don't forget to administer medications at the appointed time. Though his memory isn't always the best, my patient detests taking pills and would never ask for them" (P3).

Caregivers also stated that their irritation with the many elements of the renal diet made it more difficult to provide personal care and manage medications.

"I can deal with nutritional and hydration limits for heart failure and diabetes, but I'm not sure how you can handle all these unique needs when cooking a single meal for renal disease. The dietician definitely has to get in touch with me so I can make sure I understand what I'm meant to be doing. I have a lot of questions. I'm not sure what the information sheet means. You become so confused when you're always getting sheets on nutrition and fluids" (P11).

4.2.2.2. Subtheme 2: Lack of Knowledge about the Complexities of Hemodialysis

Another aspect of this theme dealt with the ignorance of caregivers; participants showed a limited comprehension of some of the intricate details of renal care, such as how to maintain a hemodialysis catheter or fistula. Hemodialysis catheters and fistulas are vital lifelines for patients and the way blood is transported to a hemodialysis unit. According to caregivers, they were aware of how critical it was to maintain a clean fistula or hemodialysis catheter site. They were not, however, informed about the possible difficulties that could arise, how to identify these complications, or what to do in the event that the hemodialysis catheter or fistula began to bleed. More tension resulted from this.

"I take off the plasters but am constantly afraid that something may bleed; then, what would I do? I would have to call an ambulance. I check his fistula every day to see if it bleeds, but I'm not sure what else I should be checking for" (P12).

"Determining if you should call the doctor or an ambulance adds to the already stressful situation. I don't see why no one can even answer yes or no to you or offer you counsel on this as I have no experience in the medical field" (P1).

4.2.2.3. Subtheme 3: Seeking Information and Education

All of the participants agreed that there was a need for targeted educational initiatives that would address their evolving information and knowledge requirements when it came to providing hemodialysis care. The majority of participants emphasized the idea of the committed pursuit of knowledge as a recurrent theme that emerged from the experiences of the caregivers.

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

"When medical personnel come to my father's bedside, I listen carefully to what they have to say about the drugs they are giving him. This enables me to obtain important knowledge regarding these treatments" (P9).

On the other hand, caregivers expressed anxiety over the lack of specialized training and knowledge regarding the management of their hemodialysis relatives' health.

Stated by another participant:

"We do not understand the function of these drugs, and we do not know where to buy them or how to take them correctly" (P7).

Similarly another caregiver stated that:

"Hemodialysis is beyond my comprehension, and when my son's creatinine levels hit six, the doctor said he was very ill and suggested dialysis. I knew nothing about dialysis other than this thing they put in about here (the neck). I distinctly recall stating that I would not be able to handle my son having to go through that (catheter insertion)" (P11).

4.2.3. Theme 3: Emotional and Psychological Challenges

One major element that emerges from their stories is the emotional toll that caring for individuals with end-stage renal disease (ESRD) takes on the caregivers. It became clear from the interviews that these caregivers deal with a wide range of complex emotions.

4.2.3.1. Subtheme 1: Initial Shock and Uncertainty among Caregivers:

The early emotional turmoil that primary caregivers experienced upon accepting the harsh reality of their loved one's situation is captured in this subtheme. These caregivers' tales presented lives filled with uncertainty, forcing them to adjust to the psychological and emotional strain of navigating this uncharted territory. Their lives were now marked by an acute sense of time, as well as emotions of fear and worry associated with time passing.

A female primary family caregiver who was taking care of her son in the following manner provides a clear explanation of this idea:

"Acceptance was exceedingly challenging. Since he is the only son I had, I was on the verge of passing out. I had heard that patients with kidney disease may receive HD treatment. But I didn't think it would occur in my family. When I learned about it, I felt as though my entire world was crumbling and I was unable to accept it. In addition, I thought he would pass away right away and didn't think he would live much longer" (P11).

Another caregiver stated that:

"Right then, I was at a loss for words to describe the emotion. You can probably appreciate how upsetting it must be to hear that one's kidneys are no longer functioning after only visiting the hospital for a headache and having no previous medical history. It seriously damaged both of us psychologically, me and him" (P3).

4.2.3.2. Subtheme 2: Feelings of being overwhelmed:

The emotional and psychological health of those providing care was found to suffer as a result of their attempts to balance their personal, domestic, and professional responsibilities, leaving them feeling overburdened. Because of these conflicting demands on their time and energy, caregivers found it difficult, if not impossible, to find time for themselves. As a result, they were unable to perform their multiple tasks to the best of their abilities. Numerous caregivers reported feeling anxious about their patients' health conditions as well as their own lack of leisure time. The majority struggled to find time for their own needs.

A 56-year-old man responded,

"My wife has an illness for which there is no treatment, therefore I'm constantly concerned that she might pass away" (P6)

A 25-year-old male said,

"I've been too busy taking care of my father to sit down with friends or watch a movie for a long time." (P9)

4.2.3.3. Subtheme 3: Feelings of distress and anxiety:

Due to their dread and uncertainty regarding their loved one's future care, participants expressed psychological anguish and anxiety. Concerned about the lack of direction from medical specialists and the unclear course of their loved one's sickness, caregivers acknowledged this. The fact that providing care is a full-time job that leaves many things unanswered and increases worry in caregivers meant that they were aware that as time went on, their health would also deteriorate.

"I am quite concerned about who will take care of him in the event that I am unable to care for him myself. As I age and experience health issues of my own, this is a worry of mine. He depends on me so much" (P2).

Many caregivers reported elevated levels of stress, worry, and a sense of isolation, indicating that the emotional strain extended to their mental health. One significant part of their collective experience was the complex interaction that developed between the mental health of the caregiver and the health of the patients.

A participant said that

"I'm depressed a lot because I think about my husband's condition all the time. I became mentally ill and nearly passed away" (P1).

4.2.4. Theme 4: Impact on Family Dynamics

The experiences of caregivers for patients receiving hemodialysis frequently touch on the issue of "Impact on Family Dynamics". The difficulties that the caregivers bring with them affect not only themselves but also the dynamics of the entire family. Caregivers deal with the emotional and practical fallout that permeate family life in addition to the difficulties of maintaining the health of their patients. Family relationships are altered by the stress of medical obligations, frequent hospital stays, and the psychological effects of seeing patients who are receiving hemodialysis struggle. Spouses may feel strained when the focus switches to the hemodialysis patients, and children may notice changes in attentiveness. This theme highlights the significant and complex effects that end-stage renal diseases can have on the delicate dynamics of families, necessitating caregivers to manage a complicated web of emotions and roles within the family. The subthemes that make up this theme are listed below.

4.2.4.1. Subtheme 1: Worries about Effects on Family

Parents and spouses are examples of active family members who provide care. Patients' dispositions are changed by the disease, which also modifies the circumstances in the life of the caregivers. Due to their limited social interactions, communication, and relationships with other family members, caregivers eventually experience loneliness in their lives. Family members who are ill can present difficulties for the rest of the family.

"The patient is entirely reliant on me, and if I visit the neighbor's place, he misbehaves and causes chaos in the kitchen" (P8)

Stated by one participant:

"The demands of a year-long hemodialysis regimen have prevented me from spending quality time with my eldest son, who is a high school student. My oldest kid is currently facing difficulties in his schoolwork and is suffering depressive symptoms as a result" (P2).

4.2.4.2. Subtheme 2: Changes in Relationships with Family

By devoting their time and resources to patient care, the family caregivers inadvertently created an environment that was conducive to negligence, the marginalization of other family members, and severe damage to the integrity of the family. The obstacles that caregivers of hemodialysis patients posed caused changes in the dynamics of family interactions. This subtheme explores how family members and caregivers change in their responsibilities and communication styles.

One of the caregivers shared their experiences as follow:

"Upon my arrival to assist my father with his errands, my wife and children may experience some issues at the same time. But since I'm taking care of my father at his house, I'm unable to help them. I've experienced this multiple times, which has led to a great deal of issues for my family and me" (P9).

Similarly, another caregiver said:

"I share a home with my sister. Our home is a hotbed of intense tension and anxiety when my sister's illness takes its toll. Though my other sibling is irritated and constantly complains about this circumstance, I am her sister. I'm not sure what to do" (P8).

4.2.4.3. Subtheme 3: Extended Family and Social Relationship

Due to time constraints and their devotion to the hemodialysis routine, caregivers for patients receiving hemodialysis bear a social cost. They lose out on common social encounters as a result of their dedication. When their family members are receiving hemodialysis, they are always there and make time to drive them from their house to the hospital. For the caretakers, this devotion creates a barrier to participating in their regular social activities. For them, it is difficult to build relationships with family and friends because of the importance of their presence during dialysis and their vital role in extended care.

One participant stated that:

"Other relatives and I don't get along well. Making time for my other family members at home is difficult, and visiting them is difficult. No matter how happy or sad the occasion, I can't be there. The biggest problem is that I find it difficult to set aside time for my spouse. My daughter's illness has made life extremely difficult, and I no longer feel as connected to everyone" (P7).

4.2.4.4. Subtheme 4: Lack of Social Support

It was anticipated that sources of social support would come from friends, family, coworkers, volunteers, support groups such as non-governmental organizations, and/or government agencies. But they aren't receiving the support they so need and so urgently want. The participants explicitly expected people and organizations that matched their situation to show them financial, psychological, and moral empathy.

For example, a 42-year-old lady who was her husband's principal caregiver reported the following outcome:
"There isn't any support that is appropriate for the circumstances we are currently facing. Our children cannot help me because they are not yet adults. I have to bear the entire weight. Our friends and relatives used to help us morally and spiritually, but that support has since stopped. Due to their weariness" (P7).

Another participant stated that:
"I used every resource available to me, and now that the treatment has been going on for a year and a half, I can no longer pay the cost of the treatment. I received the funds from my mother-in-law for the current session. She promised to pay for her treatment after selling her lone dairy cow. Because the cow's dairy products are her source of income, I find it disturbing to consider what might have happened to her mother" (P12)

4.2.5. Theme 5: Unbearable Economic Challenges

Throughout the experiences of caretakers for hemodialysis patients, the topic of financial challenges is recurring and significant. These families are already under a great deal of stress from the financial pressure of caring for their sick loved ones, which includes frequent hospital stays, prescription expenditures, and treatment expenses. The financial difficulties go beyond the immediate expenditures of care; they also include the price of traveling to medical facilities, the possibility of job losses for parents, and the overall effect on household finances. The caregivers voice grave worries about their financial situation and the possible effects on the welfare of their kids.

4.2.5.1. Subtheme 1: Impact on Employment and Income

The caregivers experienced strain, a decline in job performance, and a number of other issues as a result of caring for hemodialysis patients.

A caregiver who was a teacher said:
"I work as an educator. Suddenly, as I'm lecturing in the classroom, my thoughts turn to my ailing mother. I get irritated and feel so depressed that I can't focus. This problem made my work as a teacher less effective" (P5).
In addition to potentially decreasing caregiver productivity, the practice of caring for patients may also cause stress and tension in the workplace.

One of the caregivers stated:
"I work for a company. When I get a call saying, "Your son feels under the weather," I'm at a meeting. I'm at a difficult place right now and can't stop thinking about my son or leave the meeting" (P11).

4.2.5.2. Subtheme 2: Medical Expenses and Treatment Costs

The loss of financial capacity and other assets, such as losing one's job due to absenteeism, not being able to pay for one's own and one's children's education, not being able to afford basic necessities for the home, such as food, clothing, and sanitary supplies, not being able to pay rent, having to sell one's home and farmland, and being dependent on others for support, were the economic burdens that were identified. Caregivers now face ongoing challenges due to the rising costs of treatment and the scarcity of resources for the needs of other family members.

A 35-year-old woman said,
*"Since my husband can no longer work and there is no one else to provide for us financially and the government program doesn't cover all treatment costs, I have to rush every week to arrange money for travel and other expenses during treatment" (P1)*Another participant replied,

DISCUSSION

This current study attempted to investigate the challenged faced by caregivers for patients receiving hemodialysis. Out of the sixteen subthemes that came from the data analysis, this part examines and evaluates five major themes. After a thorough conversation, it became clear that the caregivers of CKD patients receiving regular hemodialysis were under more stress and had a heavier workload. The journey for dialysis, medical treatment, physical ailments, psychological problems, social anxiety, financial strain, and household or daily tasks were among the areas of reported difficulty. The opinions of caregivers on a wide range of topics, including the callous and heartless behavior of friends, family, the medical staff, the community, and the government, were constant and similar.

The caregiver's workload increases as a result of the patient's altered circumstances regarding eating, sleeping, dressing, and carrying out personal and medical duties. The caregiver also needs to adjust to the patient's closest family member now providing care. The results of this study demonstrate the substantial biological and physical obstacles that come with providing treatment for hemodialysis (HD) patients. Beyond only meeting the patient's immediate needs, the caregiver's responsibilities are multifaceted.

The key sub-theme of compulsive care compliance describes how caregivers feel compelled to rearrange their life to accommodate their patients' erratic requirements. Because HD patients have unpredictable health and require frequent treatments, they are dependent on their caregivers, making it difficult for caregivers to leave their patients alone. The results of this investigation align with other studies emphasizing that providing care for patients with chronic illnesses frequently results in caregivers' decreased autonomy and heightened responsibility (Divdar, Foroughameri, & Farokhzadian, 2019). In addition, a lot of caregivers report overcommitting themselves, postponing their own goals, or skipping out on self-care in favor of the patient. (Solaimanimoghaddam, Beydokhti, & Firouzkohi, 2024).

In agreement with this current study results, a different study found that the care life imbalance happens when the caregiver runs out of time and is unable to provide the patient with the necessary level of care (Hejazi, Hosseini, Ebadi, & Alavi Majd, 2021). Insufficient time created by providing care for patients interferes with caregivers' life patterns, as caregiving keeps people from participating in numerous activities, according to a different study (Hashimoto, Sakai, Ikeda, & Fukui, 2020).

Another study's findings showed that providing hemodialysis patients becomes very challenging, and the caregiver's way of life changes (Solaimanimoghaddam, Beydokhti, & Firouzkohi, 2024). It means that major disruption of daily life that comes with providing care for HD patients highlights the urgent need for resources and programs that focus on the well-being of caregivers.

This compounded workload emphasizes the psychological burden of caregiving. Research has indicated that providing care to individuals with Huntington's disease (HD) causes a high rate of caregiver burnout, which is typified by physical exhaustion, worry, and a loss of enthusiasm (Ghapanvari & Hosseinigolafshani, 2021). These themes align with the findings of earlier research projects (Hejazi, Hosseini, Ebadi, & Majd, 2021; Nkuranyabahizi et al., 2021; Rajkhowa, 2019). Based on study on family caregivers of stroke patients, which showed a considerable influence on physical capacity due to the patients' long-term care, these different themes' findings were developed. According to this review, family caregivers' physical capability issue was primarily caused by exhaustion (Nimah et al., 2024).

According to the research, hemodialysis patients' caregivers' face several difficulties as a result of their lack of understanding about various aspects of providing care, including medicine administration, personal hygiene, nutritional requirements, and home care. Deficits like these can make caregivers feel pressured and overworked, which can result in less than ideal patient care and a decline in caregiver wellbeing. In particular, for patients with chronic kidney disease (CKD), recent studies highlight the significance of comprehensive training and unambiguous, straightforward communication regarding drug regimens from healthcare professionals to caregivers (Nkuranyabahizi et al., 2021).

The results of the present study demonstrated that the treatment-related challenges that the caregivers reported were primarily brought on by the treating team members' inadequate communication abilities. Family caregivers frequently lack the information necessary to offer quality nursing and medical care, as well as the readiness to provide care. The primary reason for this is that the healthcare practitioners don't offer much advice. In order to offer CKD patients with comprehensive medical treatment, it is crucial to increase the capacity of medical professionals as well as other health workers like dieticians, dialysis technicians, and staff nurses. The load and stress on caregivers will be lessened by effective communication and knowledge. It is recommended that clinicians conduct periodic screenings of caregivers to identify unfavorable physical and psychological symptoms early on and provide suitable remedies (Surendran, Venugopal, Dongre, & Paninjukunnath, 2018).

The psychological well-being of family caregivers is also impacted by long-term caregiving efforts. Different themes related to psychological states include ambivalence in life status, mental and psychological issues, mental tiredness, deprivation of basic necessities, spiritual issues, adaptations and feelings that arise from caring, and coping methods. The chronic nature of the disease, the physical state of the patients, the drugs, the diet, the difficulties following hemodialysis, and the progressive nature of the care all contribute to the significant stress in this study. Anxiety was shown to be high among the caregivers of hemodialysis patients, according to a comparable Iranian study. It was thought that having a primary caregiver interfered with family health because it was a stressful role (Salehitali et al., 2018).

Another finding of the current study, which also showed that caregivers face psychological barriers, is that caregivers believe authorities should pay greater attention to the needs and difficulties faced by hemodialysis patients. Major concerns expressed by all participants were the unavailability of insurance coverage for some of the most essential medications needed by hemodialysis patients, as well as their availability (Ghapanvari & Hosseinigolafshani, 2021). All of this is in line with the findings of the current study. The several themes of family caregiver difficulties' psychological state align with those of earlier research (Abebe et al., 2022) (Nkuranyabahizi et al., 2021).

Chronic illness patients experience severe psychological issues. The psychological stability of patients is significantly impacted by therapeutic methods, care, and medicines. Family caregivers are impacted in turn by the fluctuating psychosocial states of CKD patients. It is challenging for family caregivers to provide care for depressed patients with chronic kidney disease (CKD) (Wilianarti, Wulandari, Ghufron, & Rahman, 2022). The patients are unable to adhere to the dialysis protocol because of their intense sadness. The psychological well-being of CKD patients and their family caregivers is also influenced by adjustments made to expectations and the course of their disease (Nimah et al., 2024).

Moreover, family caregivers' care of patients with chronic kidney disease (CKD) may lead to social relations issues. Various themes, such as social disturbance, collaborative care, and family or daily life, are among the problems in this review. Further social issues resulted from the patient and caregiver being isolated due to the illness and dialysis, as well as the caregiver's social relationships becoming limited, as this study has shown. A number of social relations themes align with those found in earlier research carried out by (Abebe et al., 2022) (Nkuranyabahizi et al., 2021).

Another study with aligned results found that the high burden of care in hospitals and at home makes caregivers' social issues worse. Caregivers have fewer social ties to both their professions and other people. Both the patient and the caregiver experience social isolation and a reduction in social ties as a result of the patients' excessive dependency. In addition, because they have a lot of caregiving responsibilities, most of the caregivers in the study experience social isolation, health issues, and a lack of time. In order to help caregivers coordinate and manage the care of hemodialysis patients, it is necessary to provide critical care services and provide psychosocial support (Adejumo, Iyawe, Akinbodewa, Abolarin, & Alli, 2019).

The findings of the examination of these themes are in line with a prior study that demonstrated that family caregivers' social relationships become increasingly difficult as the care load increases (Nimah et al., 2024).

Our study found that it was challenging to get a wide range of information required from healthcare experts, which added to the anxiety and tension that caregivers felt. Information regarding care was required, in addition to details on services and other forms of support, such as financial information. This occurrence was similar to what caregivers in other nations have experienced, where their psychological wellbeing declined as a result of increased caregiver load brought on by their dissatisfaction with healthcare providers' information supply (Matthews, McKeaveney, Noble, & Reid, 2024).

One of the main issues of this study is the caregiver's financial burden. The more the patient's condition deteriorates, the more expensive treatment and living expenses for the caregiver become. According to a different study, which is consistent with the results of this one, one of the biggest obstacles faced by patients is the rising costs of hemodialysis and kidney transplant treatment. The study also found that a considerable percentage of patients' treatment expenses vary based on whether they live in a developed, developing, or underdeveloped country. Different countries have different percentages of patients who pay out-of-pocket for medical care (Shekhani & Lanewala, 2021).

One of the difficulties faced by hemodialysis caregivers, which results in issues for the patient and family, is the rise in family expenses, according to Torres et al. (2021) in their study carried out in the Philippines. Because they don't have spare time, family members are unable to make extra money. The patient's non-medical and medical costs are the main source of the financial burden (Torres et al., 2021). In addition, there are indirect costs brought on by a decline in household income and fewer options for earning extra money (Northall et al., 2020). According to a different study, hemodialysis patients place a significant financial strain on their caregivers. This emphasizes the need for policies and programs that lessen this load on at-home caregivers and offer patients and caregivers social and financial support (Solaimanimoghaddam, Beydokhti, & Firouzkohi, 2024).

CONCLUSION

The primary caregivers of hemodialysis patients encounter numerous obstacles that profoundly affect all facets of their lives. They have to physically and mentally follow rigid care regimens, deal with care fatigue, adjust to new lifestyles, and strike a balance between their personal lives and their caregiving obligations. Many caregivers also suffer from a lack of information, which makes them seek out further education. This is especially true when it comes to managing medications and comprehending the nuances of the patient's condition. The emotional toll is significant; while they adjust to their new role as caregivers, initial feelings of shock, distress, and anxiety are typical.

Family dynamics frequently change, resulting in strained relationships, worries about how it will affect social connections and extended family, and a lack of social support. Stress is further compounded by financial obligations, such as medical costs and possible income loss from less work prospects. When taken as a whole, these difficulties put primary caregivers under a complicated and varied burden that compromises their resilience and general well-being.

Recommendations

Improved Programs for Emotional Support: Create and implement customized programs for emotional support that are tailored to the particular emotional difficulties that caregivers encounter. Counseling services, support groups, and other tools to assist them in navigating the emotional complexity of managing a patient's chronic illness may be included in these programs.

Workshops and Educational Materials: Provide caregivers thorough and easily accessible teaching materials that concentrate on the medical aspects of chronic renal failure, hemodialysis techniques, and possible side effects. Workshops might be held to provide moms with the information and abilities they need to confidently handle their patient's illness.

Strengthening Support Networks: Encourage caregivers who are going through comparable difficulties to establish and fortify support networks. This could entail setting up local support groups, forming online communities, or providing forums where people can exchange stories and guidance.

Interventions Focused on Families: Provide treatments that acknowledge how a patient's chronic illness affects the whole family. Family-centered treatment should take into account the emotional needs and well-being of spouses, siblings, and other family members in addition to the impacted patient.

Programs for Financial Assistance: Establish financial aid initiatives to lessen the financial burden of medical bills and treatment expenditures. Assist families who are struggling financially as a result of their patient's chronic disease by working with appropriate organizations and governmental institutions.

Limitations

It's critical to acknowledge some limitations, even in light of the insightful knowledge obtained from the qualitative study on caregivers' experiences with patients who have chronic kidney disorders. Initially, the study's limited sample size may limit the generalizability of the results, which could restrict their relevance to a larger group of caregivers in comparable circumstances. Furthermore, given how much experiences can change between locations and cultural backgrounds, the study's emphasis on a particular geographic or cultural setting may induce bias. Given that individuals who volunteered to participate might have different viewpoints than those who declined to participate, it is important to recognize the possibility of sampling bias. Additionally, because the study is qualitative, subjectivity and recall bias may be present because individuals might not fully recall some parts of their experiences. Because of the study's focus on primary caregivers, the insights may not be as complete because other caregivers' viewpoints may be overlooked.

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