

## Lived Experiences of Patients with End-Stage Renal Disease (ESRD) on Maintenance Hemodialysis at Machakos County, Kenya

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### Abstract

End-Stage Renal Disease (ESRD) is the final stage of chronic kidney disease that requires lifelong renal replacement therapy such as hemodialysis or kidney transplantation for survival. Despite the increasing burden of ESRD in Kenya, little is known about the lived experiences of patients undergoing maintenance hemodialysis, particularly in low-resource settings. This study explored the lived experiences of patients with ESRD receiving maintenance hemodialysis at Machakos County Referral Hospital, Kenya, with an emphasis on changes in daily routines and coping mechanisms resulting from hemodialysis. The study adopted a descriptive phenomenological qualitative research design. Sixteen patients who had been on maintenance hemodialysis for at least one year were purposively selected. Data were collected through semi-structured in-depth interviews conducted in English and Kiswahili. Interviews were audio-recorded, transcribed verbatim, and thematically analyzed using Braun and Clarke's six-phase framework with support from ATLAS.ti version 8.4.4. Findings revealed that maintenance hemodialysis significantly affected patients' physical, psychological, social, and economic well-being. Five major themes emerged: seriousness of the disease, challenges of accessing hemodialysis, financial constraints, restricted life, and psychological impacts. Participants reported high treatment and transport costs, fatigue, dietary and fluid restrictions, disruption of social and work life, machine breakdowns, anxiety, depression, altered body image, and dependence on dialysis machines and family support. Religious faith and family support emerged as the main coping mechanisms among participants. The study concludes that ESRD and maintenance hemodialysis pose profound, multidimensional challenges for patients and their families. The study recommends expanding health insurance coverage for dialysis-related costs, establishing satellite dialysis centers in rural areas, integrating psychosocial support into renal care, strengthening community-based kidney disease awareness programs, and forming patient support groups to improve the quality of life for patients on maintenance hemodialysis.

**Keywords:** *End-Stage Renal Disease, Hemodialysis, Lived Experiences, Quality of Life, Coping Mechanisms, Kenya.*

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## 1. Introduction

End-Stage Renal Disease (ESRD) is the final stage of chronic kidney disease in which the kidneys permanently lose their ability to perform normal physiological functions, requiring renal replacement therapy such as hemodialysis or kidney transplantation for survival. According to Benjamin and Lappin (2021), ESRD occurs when kidney function declines to less than 15% of normal capacity, while Ke et al. (2022) describe it as an irreversible condition associated with severe health complications and dependence on lifelong treatment. Patients diagnosed with ESRD are therefore forced to make major lifestyle adjustments to accommodate ongoing treatment and disease management.

The burden of ESRD is influenced by several risk factors, including diabetes mellitus, hypertension, recurrent kidney infections, age, gender, and socioeconomic status. Studies by Luyckx et al. (2018) and Ke et al. (2022) indicate that the burden is particularly severe in low- and middle-income countries due to limited healthcare resources, inadequate dialysis access, and high treatment costs. In Kenya, dialysis services have expanded over the years, with more than 200 dialysis units established nationwide and partial support provided through the national insurance scheme. However, patients on maintenance hemodialysis are still required to adhere to strict dietary and fluid restrictions, frequent hospital visits, and major lifestyle changes that affect their physical, social, and psychological well-being (Beerendrakumar et al., 2018; Maritim et al., 2022).

In Kenya, the burden of chronic kidney disease and ESRD continues to rise, with the Ministry of Health estimating that over 4 million Kenyans are living with chronic kidney disease and approximately 10,000 patients have ESRD. Despite this growing burden, access to dialysis and specialized renal care remains inadequate, especially among low-income and rural populations (MOH, 2017; Maritim et al., 2022). Previous studies have shown that patients on maintenance hemodialysis experience reduced physical activity, social disruption, emotional distress, financial strain, and dependence on dialysis machines, all of which negatively affect their quality of life (Beng et al., 2019; Tadesse et al., 2021).

Although several studies have examined the medical and economic burden of kidney disease, there remains limited qualitative evidence on the lived experiences and coping mechanisms of ESRD patients in Kenya, particularly among patients from low-income backgrounds. Existing literature has largely focused on disease prevalence, risk factors, and healthcare access, with little emphasis on how patients navigate daily life while undergoing maintenance hemodialysis. Understanding these experiences is important for informing patient-centered care, improving psychosocial support, and guiding evidence-based healthcare policies and interventions to improve the quality of life for ESRD patients in Kenya.

### Specific Objectives

- i. To explore how the routines of daily life change for ESRD patients on maintenance hemodialysis
- ii. To explore how patients with ESRD on maintenance hemodialysis cope with challenges arising from maintenance hemodialysis.

## 2. Literature Review

### 2.1 Theoretical Review

Dorothea Orem's Self-Care Deficit Theory of Nursing was used. The primary rationale is that the study is anchored in live patients with ESRD on maintenance hemodialysis. Dorothea Orem's Self-Care Theory helps understand the practice of activities that individuals undertake to maintain life, improve health, and promote well-being. Khademian et al. (2020) noted that Orem's nursing theory focuses on the concept of patient experiences with chronic diseases, their need motivation, experiences, and skills to undertake behaviors and practices needed for maintaining and improving health and quality of life. The theory serves as a model for evaluating patients' experiences and lived experiences with dialysis for end-stage renal disease. The components required for assessing lived experiences include the aspects of nursing systems, patient self-care deficit, and self-care abilities, in addition to the required maintenance hemodialysis.

### 2.2 Seriousness of End-Stage Renal Disease

End-stage renal disease is a fatal condition characterized by irreversible loss of kidney function, in which the glomerular filtration rate drops below 15 mL/min/1.73m (Jager et al., 2019). At this point, the kidneys can no longer regulate water balance, and electrolyte and metabolic balance cannot be maintained, resulting in the buildup of uremic toxins, profound anemia, hypertension, and cardiovascular effects (Murdeswar & Anjum, 2023). Without renal replacement therapy, the patient has less than a few months to live; it is therefore regarded as one of the worst non-communicable diseases in the world (Flythe et al., 2024).

ESRD's severity extends beyond its physical decline. Worldwide, more than 850 million people are affected by CKD, with ESRD representing a disproportionate number of deaths and disabilities adjusted life years (Jager et al., 2019). Sub-Saharan Africa is characterized by delayed diagnosis due to the absence of screening in primary health care. Most patients with chronic kidney disease first reach definitive care in a uremic state requiring immediate emergency dialysis" (Gebrie et al., 2023). High initial death rates in HD patients during the first year of dialysis are also reported as being as high as 20-40% in low-income settings (Mengistu & Ejigu, 2022). These numbers suggest that ESRD cannot be regarded as just a chronic illness, but as a persistent life-threatening disease requiring continuous medical attention.

No less important is the patient's symptom burden. Such symptoms as fatigue, pruritus, sleep deprivation, muscle cramps, and cognitive disturbances can present concomitantly with iatrogenic problems such as hypotension within dialysis and vascular access infection (Hall et al., 2020). The combination of burdens leads to End Stage Renal Disease being compared to cancer (multiple advanced types) in terms of its disablement level (Goh & Griva, 2018).

### **2.2.1 The Role of Hemodialysis for Patients with End-Stage Renal Disease**

Hemodialysis is an indispensable component of the management of patients with ESRD. It serves as a life-sustaining renal replacement therapy by artificially substituting for the excretory and homeostatic functions of non-functioning kidneys. Hemodialysis' mechanisms remove uremic toxins, fluid, and electrolytes from the patient's blood, thereby preventing fatal consequences of uremic disease, hyperkalemia, metabolic acidosis, and fluid overload (Murdeshwar & Anjum, 2023). Physiologically, hemodialysis not only enhances life expectancy in ESRD patients ineligible for renal transplantation or on the wait list for renal transplant, but it also postpones an otherwise imminent death in ESRD patients (Lakshminarayana et al., 2017). Furthermore, the authors note that hemodialysis has a series of beneficial physiological effects, such as the prevention of pulmonary congestion, improved cardiac performance via better fluid balance, and improved anemia symptoms, when employed alongside erythropoiesis-stimulating agents (ESAs) (Lakshminarayana et al., 2017). While indispensable for the survival of ESRD patients, hemodialysis is not a curative modality. ESRD patients continue to be chronic disease patients in that they will experience progressive comorbidity such as mineral and bone disorders, protein-energy wasting, and cardiovascular disease (Flythe et al., 2024). Consequently, hemodialysis may act as both a bridge to transplantation and an enduring replacement modality, which greatly influences the physiological, psychosocial, and biological existence of ESRD patients.

### **2.2.2 Challenges in Accessing Hemodialysis Services for Patients with ESRD**

Although HD is readily available in some tertiary care centers, access is not universal. A major problem is the unavailability of functioning dialysis machines and trained technicians. There is usually one dialysis unit in a tertiary care center serving several hundred patients (Kenya), and similarly, there are few machines in single dialysis units in Ethiopia, which has led to overtime of the nurses and patients sharing an appointment (Gebrie et al., 2023; Mwai & Muriithi, 2023). Breakdowns are frequent because few of these centers have backup equipment or maintenance contracts. Failure of a machine will send the patient either to a center hundreds of miles away or will take several days to repair, and these delays are fatal because uremic patients have such narrow safety margins (Shimels et al., 2021).

Service maldistribution due to geography constitutes a major hurdle to accessing HD. As many of the HD centers are located in the capitals, many rural-based patients have to relocate or travel from their homesteads to the centers and back twice per week (which is costly, given it is thrice weekly), exhausting both the household's financial and physical resources (Barasa et al., 2018). Even when the costs of transport, accommodation, and lost earnings exceed the subsidized dialysis fees the households must meet, resulting in catastrophic health expenditure (Mwai & Muriithi, 2023). In Kenya, claims repudiations, delays, and threats of facility closures following the shift of NHIF to SHA leave patients unsure whether their dialysis sessions will be covered (Kenya Insights, 2025; Scholar Media Africa, 2025; The Africa Report, 2024). There have been reports of some private clinics suspending HD due to the inability to cover the cost of consumables at the proposed new Social Health Insurance Fund (SHIF) tariff (Ministry of Health, Kenya, 2024; Nation Media Group, 2024).

Additional systemic problems include inconsistent delivery of dialysate, dialyzers, and erythropoietin; persistent power shortages that disrupt sessions; and a scarcity of vascular access surgery, meaning most patients start dialysis with a temporary catheter and are at greater risk of infection (Lakshminarayana et al., 2017). In total, these obstacles turn what is already a life-preserving intervention into a high-stakes operation that the patient must continually navigate.

### **3. Methodology**

The study adopted a descriptive phenomenological qualitative research design to explore the lived experiences of patients with End-Stage Renal Disease (ESRD) on maintenance hemodialysis at Machakos County Referral Hospital, Kenya. The target population comprised adult ESRD patients who had been on maintenance hemodialysis for more than one year. Purposive sampling was used to recruit participants who could provide rich, relevant information about their experiences with dialysis treatment. Data saturation was achieved after interviewing 16 participants. Data were collected through semi-structured in-depth interviews conducted in English or Kiswahili between March and August 2023.

The interviews were audio-recorded, transcribed verbatim, and thematically analyzed using Braun and Clarke's six-phase framework, with support from ATLAS.ti software. The study explored participants' experiences of changes in daily routines, coping mechanisms, and quality of life during hemodialysis. To ensure rigor and trustworthiness, the study applied Guba and Lincoln's criteria of credibility, dependability, transferability, and confirmability. Ethical approvals were obtained from relevant institutions, and informed consent, confidentiality, and voluntary participation were upheld throughout the study.

### **4. Results**

#### **4.1 Participant Demographics and Clinical Characteristics**

There were many demographic variables in the study group, and clinical experience was common among the subjects. As shown in Table 1, most subjects were diagnosed with the condition within the last 2 to 7 years. There was also wide variation in dialysis duration among the subjects, ranging from 2 months to 8 years. Many of the subjects were reported to have suffered from diabetes mellitus and hypertension as possible causes for their medical condition. The demographic distribution is similar to the national trends observed in Kenya, where non-communicable diseases are the major risk factors for ESRD. Background information on these characteristics helps the researcher design interventions aligned with the needs of this patient group.

**Table 1: Demographic and Clinical Characteristics of Study Participants**

Characteristic	Category	n (%)
Gender	Male	8 (50.0)
	Female	8 (50.0)
Age Range	30-35 years	3 (18.8)
	36-40 years	5 (31.3)
	41-50 years	4 (25.0)
	51-68 years	4 (25.0)
Education Level	Primary/Secondary	6 (37.5)
	College/Diploma	7 (43.8)
	University	3 (18.8)
Residence Type	Rural	11 (68.8)
	Urban	5 (31.3)
Marital Status	Married	10 (62.5)
	Single/Divorced	6 (37.5)
Duration on Dialysis	< 1 year	4 (25.0)
	1-3 years	8 (50.0)
	> 3 years	4 (25.0)
Underlying Condition	Diabetes	10 (62.5)
	Hypertension	8 (50.0)
	Unknown/Familial	4 (25.0)
Employment Before ESRD	Employed	5 (31.3)
	Self-employed	7 (43.8)
	Unemployed	4 (25.0)
Current Employment	Working (reduced)	3 (18.8)
	Stopped working	11 (68.8)
	Retired/Unable	2 (12.5)

Note: Some participants had multiple underlying conditions. All participants are identified by codes (P1-P16) to maintain confidentiality.

**Table 2: Summary of Major Themes and Sub-themes Mapped to Research Objectives**

Research Objective	Theme	Sub-themes
1. To explore how the quality of life changes for ESRD patients on maintenance hemodialysis	Theme 1: The Seriousness of the Disease	Worry of poor outcomes and lifelong treatment Restrictions on full participation in social activities
	Theme 4: Restricted Life	Restrictions on fluids and diet Fatigue from dialysis and decreased energy levels Implications from life plans
	Theme 5: Psychological Impacts	Altered body image Sleep disturbance Depression and anxiety symptoms
2. To explore how patients with ESRD on maintenance hemodialysis cope with challenges arising from maintenance hemodialysis	Theme 2: Challenges of Getting Hemodialysis	Life struggles with the disease and machine breakdowns Boring nature of intradialysis experience
	Theme 3: Financial Constraints	Financial challenges and the need to travel Work-life balance and implications for financial abilities

## 4.2 Theme 1: The Seriousness of the Disease

### 4.2.1 Worry of Poor Outcomes and Lifelong Treatment

All participants highlighted their fears related to prognosis and the responsibility for being on lifelong medication. At first, they experienced high levels of emotions, namely fear, shock, and uncertainty about their survival after diagnosis. The participant named P1, who was a 42-year-old farmer, explained his fears, saying, "*It made me feel like all hope was lost since, for the diabetes, I was struggling with the medicines anyway, and so I felt like this was an extra burden.*" It shows how psychologically difficult it can be to deal with multiple problems simultaneously. Emotional well-being is directly associated with quality of life, as psychological issues may worsen physical condition.

The threat of having to undergo lifelong dialysis became a recurring issue in all interviews. Participant 4 (P4), an adult female aged 38 years, said, "*I think for a lifetime now*" in reference

to treatment duration, while participant 9 (P9), an adult male aged 45 years, a hardware shop owner, was equally wary when he said, *"They told me that I am going to be doing it for the rest of my life."* This realization forced the interviewees to consider issues of death and yet plan on how to cope with the treatment throughout their lives.

Other participants voiced concerns about the length of treatment and its potential impact on family well-being. When the doctor informed me this is for life, unless I receive a transplant, I was disappointed, and I just thought about my children, my wife...", said P13, a 52-year-old retired civil servant. *"If I die, what will happen to them? Who will take care of them?"* Participant 3 (P3), a 33-year-old male vegetable seller, added, "At my age, I should be expanding my business, not asking myself if *I will last another month*". But Participant 14 (P14), a 35-year-old female hairdresser, shared, *"Whenever I come for dialysis, I meet people who are very ill, and sometimes I have seen people die, I wonder if someday it will be me. I pray every day that God will keep me alive for my children.* The statements show how personal fears of death and family responsibility issues converge, and how ESRD is not only a disease of individual patients but a family disease as well. This family anxiety is related to a general idea of dependency and role shifts in families.

This ambiguity on how the course of treatment might go contributed immensely to continuous fear amongst participants. In illustration, Participant 15 (P15) stated his experience as a 48-year-old man, a driver, as follows: *"You don't actually know if you are recovering properly. Some days you feel good, while at other times you feel bad. The doctors do not even inform you about your life expectancy. It is really hard for me to cope with such ambiguity."* On the same note, Participant 16 (P16), who was a 56-year-old woman, stated: *"I have had this problem for about three years now. My worry lies in whether I can make it to five years, to ten years. Transplant is said to be the only hope for me, but how do I go about finding the kidney? Not to mention the cost involved."*

Without a definitive prognosis and with few options for curative measures such as transplantation, major uncertainty reigns, which condemns patients to a state of chronic anxiety. The uncertainty directly affects patients' capacity to plan in the long run and also leaves persistent psychological distress. Healthcare providers need culturally competent strategies to communicate prognosis and to accept and support patients when faced with uncertainty.

#### **4.2.2 Restrictions on Full Participation in Social Activities**

The disease significantly reduced the participants' ability to participate in the social activities that they used to enjoy. P7, a 40-year-old domestic worker, stated that opportunities are also being denied her: *"I am not able to get jobs such as washing and lifting heavy due to the poor condition of my body."* Likewise, P5, a 44-year-old patient, had to give up playing football with women and walking: *"I used to play football with the women, I used to walk a lot more, but now I can't walk so much."* The limitations stem from the disease process's physical constraints and the demanding treatment, which depletes the energy reserves required for recreational and occupational activities.

There was a significant decline in community and religious involvement among the participant group. P2, a 51-year-old male patient, explained: *"I'm not going to church anymore, I've stopped going to chamas, a number of other things."* This social isolation leads to feelings of

*loneliness and lowers quality of life, and can exacerbate the psychological effects of the disease by limiting the person's social supports and places providing meaning.* In Kenyan culture, the absence of religious and community ties is especially significant, as these ties offer social identity and support during a crisis. Social isolation is integral to social care and must be considered in healthcare interventions.

Other participants talked about resigning from community and leadership roles due to illness. P13 also described: "Before this sickness, *I was very active in our village development committee; we were meeting every week and discussing projects to work on in our village; now we aren't able to meet because I am too tired, we still try to contact me, but they know that I don't.*" P14 had similar experiences: "*I was the chairlady of our women's group, and we met twice a month, but now I had to resign as dialysis is twice a week and I cannot keep up, I miss those (gatherings) very much, it was not just about money, it was about friendship and support.*" Beyond the physical limitations related to ESRD, the patients are forced to give up the role of leadership and social responsibility, which they were accustomed to and enjoyed prior to ESRD.

### **4.3 Theme 4: Restricted Life**

#### **4.3.1 Restrictions on Fluids and Diet**

The dietary changes entailed significant changes in the patients' and their families' lifestyles. The participants were advised to consume about 5 cups of fluids per day, minimize sodium intake, and avoid foods rich in phosphorus and potassium. Patient P12 explained the extent of these changes as follows: "They said I have to use water three times a day and three times at night. They told me I have to use five cups per day altogether." These drastic limitations require continuous diligence and abstinence, turning everyday activities such as eating and drinking into stressful experiences and health hazards if the rules are not adhered to. The dietary limitations are also associated with broader considerations of quality of life, since food and drink decisions transcend nutrition and encompass social interaction and culture.

Separate meals prepared for patients added to the financial strain caused by dietary restrictions. P1 added: "When my wife cooks for the family, she has to cook special food for me. So that's an additional budget. Special diets, supplements, and recommended foods are heavily taxed, already limited resources." The need for some family members to prepare meals separately imposes a financial burden and increased workload on the women, usually the head of the household, who are expected to handle multiple cooking tasks. Dietary management, therefore, has a household-level effect beyond the patient, and the dietary intervention will be at the household level.

The financial difficulties participants faced in purchasing recommended foods and the social isolation they experienced while following diets were described. P15 elaborated: "The doctor told me that I can't eat bananas, I can't eat tomatoes, I can't eat avocados. These are the cheap foods that we have at home. The nutritionist told me to eat fish, eat chicken – but where is the money? Even though I know what it is I should eat, I eat ugali and sukuma wiki for most part of the day." P8, a 36-year-old male tailor, further commented: "*I was a tailor, but had to close my business due to dialysis, and I can no longer afford to buy special foods.*" P16 shared the social impact: "When I go to my family, everyone eats and drinks freely; I have to sit there

with my little cup of water and my special food, and people ask me, 'Why don't you eat? You're being a big man!' *They think you are proud of your little cup of water. Both of those are painful. Sometimes I just stay home over here to avoid such.*" The gap between medical advice and economic results is that patients are unable to consistently maintain their diet, and a lack of social awareness of the diet can lead to embarrassment and isolation.

#### 4.3.2 Fatigue from Dialysis and Decreased Energy Levels

This post-dialysis fatigue became a universal phenomenon, an essential aspect of the lives of those going through this process. In every interview, individuals reported having had to deal with extremely high levels of fatigue following each session of dialysis; so high was the degree of exhaustion that it would take extended periods of time to recover. P2 described this feeling well in their own words: *"I sleep a lot because I get tired a lot. When I get home, I am very weak."* As a consequence of such fatigue, these people found themselves unable to complete ordinary household chores and work-related tasks, and to engage in social life, thus reinforcing the vicious circle in which patients find themselves, where the process designed to help them survive ends up making their lives difficult. Indeed, this problem is exacerbated by the fact that patients must undergo this process 2-3 times per week.

The cycle of post-dialysis fatigue is detrimental to continued recovery and functioning. As described by P13, *"Monday – I get my dialysis done. Tuesday – I'm completely tired, and I slept the whole day. Wednesday – I start feeling okay, Thursday I have to go for another dialysis, and then there's no recovery for me, nor do I feel good. Even simple things like having a bath, walking to the grocery store make me tired."* The effect of this continuous fatigue makes it difficult for patients to return to their normal duties and leads to progressive deconditioning, creating a cycle of diminishing physical ability. Treatment-related fatigue affects various aspects of life, including the ability to work, function within families, and manage personal care routines.

Parenting skills and the family's role were especially affected by fatigue. P14 explained, *"My kids need me, but after dialysis, I don't have the energy to do their homework or cook good food for them. This is not fair to them; it shouldn't be like this because they are only 12 years old."* P11, a 50-year-old female farmer, said: *"The extreme tiredness after dialysis makes it hard for me to work on my farm, and now we have no income or crops."* Fatigue makes it impossible to fulfill parenting roles, which can overload children and impact their development and education. Parental illness has intergenerational effects and is a consequence of ESRD that is not often discussed.

#### 4.3.3 Implications from Life Plans

The condition required participants to rethink their life goals and plans to a great extent. It had a profound effect on educational goals, professional growth, and family plans. Parents felt inadequate in providing for their children's future; some were selling family property that was to be passed down to their children. P1 voiced: *"We are going to be compelled to sell the family property that my kids need to have."* Giving up a future, secure existence for a life of survival in the present leads to deep dismay when patients see the breadwinners of tomorrow taken away. The loss of life plans is linked to the psychological themes of hopelessness and financial themes of intergenerational poverty.

Specific plans were mentioned but not implemented due to illness. P15 shared, *"I had some intentions of building a house for my family that I now can't on the grounds that all my money went to the hospital, the materials are there, but my dream of leaving a nice house to my children is over."* P16 said that their plans for their son to attend Form One this year were derailed by illness: *"My son was supposed to join Form One this year. We have paid for his secondary education up to Form One; now this sickness has come, and we used everything we saved for him for the school fees for the year. Now he is at home, he misses school, and his future is being affected because of my kidneys, and this pain is worse than the pain of sickness."* When resources are diverted from future-oriented investments to immediate survival needs, it is not only a matter of dollars and cents; it's about dreams and aspirations dying. Children's education is affected, and this has an impact on the next generations that can be inter-generational, locking families in a cycle of poverty. Social protection measures need to have provisions to support continuing children's schooling and basic family investments in the event of parents' ill health.

#### **4.4 Theme 5: Psychological Impacts**

##### **4.4.1 Altered Body Image**

The visible components of dialysis therapy had a significant impact on patients' self-image formation. Catheters and fistulas influenced the choice of certain types of clothing and feelings during social activities. As P9 explained, "you cannot dress the way you used to be dressed. Because now there are things you are hiding. You have to change." It is clear that the necessity of covering certain parts of the body due to illness changes clothing's function from a mode of expression to a means of concealment, demonstrating how illness affects people's self-image. Issues of body image were also related to social isolation, as patients avoided any situation where their changed appearance was noticeable.

Changes in the body that could be seen had a specific impact on gender identity. P1 said: "As a man, it's embarrassing, you know, as a man you don't want to show weakness, and using a catheter is sometimes seen as a weakness." The cultural context of gender norms, associated with physical strength, invulnerability, and weakness, is embodied in the interpretation of physical signs of illness as weakness. Body image and gender identity issues intersect to produce multiple layers of psychological distress that need culturally informed interventions.

Female participants described visible scarring and its social impact. P14 shared: "I have a big scar on my arm where the fistula is. It is very visible. People stare at it. Some ask what happened. I feel ashamed to explain that my kidney failed. Before, I was a beautiful woman, but now I feel ugly. I avoid wearing short sleeves or sleeveless dresses even when it is hot." P15 described appearance changes: "I have lost so much weight. My clothes don't fit anymore. People who haven't seen me in months don't recognize me. They say I look like I am dying. My skin is dark and dry. I look in the mirror, and I don't see myself anymore. I see a sick old man."

The physical changes bring a sense of separation from one's body, as the image no longer reflects one's self-perception. This body alienation can be a cause for depression, and can even impact treatment compliance if the patients believe their changed body is proof of their terminal illness.

#### 4.4.2 Sleep Disturbance

Disease process and treatment protocols had major effects on sleep patterns. There was a tendency to need more sleep after dialysis and to fall asleep. P2 explained: "I sleep a lot; they have to cook for me, and life after dialysis isn't the easiest, but again, I'm stronger than before the dialysis." Physical exhaustion, worry about the treatment and side effects of medication, led to complex sleep disturbances, which impacted the quality of life and recovery between sessions. Sleep disruption adds to fatigue, mood disturbances, and loss of cognitive function, and on top of other illness effects.

Participants reported specific sleep issues such as waking up multiple times, nightmares, and disturbance of the sleep-wake cycle. P16 explained: "Nighttime I don't get a real good sleep, and I do have to get up and pee a lot throughout the night, but it's not like I am drinking a lot of water, my legs cramp and hurt, and I worry about money, I worry about my kids, I worry if I'm going to be around to see them grow up. I think those things keep me up at night, and during the day, after dialysis, I sleep too much and can't get up. My sleep pattern is all mixed up." P13 added: "Some nights, I have nightmares that the dialysis machine will stop working, or that I will die on dialysis. I wake up sweating and frightened that something's wrong; my wife says sometimes I shout in my sleep; it takes its toll on her sleep too; we are both tired all the time; the dialysis has deprived us of rest." When patients and family members are unable to sleep, their sleep is affected. This generates household-level fatigue, reducing the household's ability to cope.

#### 4.4.3 Depression and Anxiety Symptoms

In addition to body image and sleep problems, participants had substantial depression and anxiety symptoms. These psychological impacts deeply affected overall well-being and coping abilities. Symptoms included ongoing sadness and crying, significant anxiety, and suicidal thoughts. The high prevalence of psychological distress reflects the overwhelming burden of ESRD, and the fact that patients experience physical suffering, financial devastation, social losses, and existential threat. Depression and anxiety are not treated, and this in turn decreases adherence to treatment, physical outcomes, and quality of life, and this becomes a negative spiral.

Symptoms of depression included hopelessness, withdrawal, and, in some cases, suicidal thoughts. P13 told me: "I feel like there are days when I don't want to wake up and another day of having to struggle. The sadness is like a stone on my chest. I cry when no one is looking, and I wonder if my family would be better off without me, if my family would be better off without this burden on them. P14 expressed anxiety as follows: "My heart races all the time. I worry about everything – will I make it to the hospital, will this machine work, will I make it through this session, what will happen to my kids if I die. The worry never stops, and in the end, it is exhausting to be anxious every single day. Suicidal ideation – even when those thoughts are not put into action – signals serious psychological pain that needs an immediate professional response. The co-occurrence of depression, anxiety, and suicidal ideation therefore poses a pressing need for safety that must be understood and addressed by health care providers.

Psychological distress manifested as irritability and emotional lability in family relations. P15 explained: "I get irritable with family, get angry at little things, then I feel bad for getting mad at them. They are trying to help me, but my depression pushes them away. I know that I am not the same person anymore, but I can't control my feelings of depression." Psychological distress is experienced beyond a person's illness and causes secondary harm that damages the patient's critical support systems.

The six themes identified comprehensively address all four research objectives. A compiled analysis of the lived experiences of 16 participants provides essential insights and helps the researcher craft interventions that address actual patient needs rather than assumptions about those needs.

## **4.5 Theme 2: Challenges of Getting Hemodialysis**

### **4.5.1 Life Struggles from the Disease and Machine Breakdowns**

For participants, the major hurdles to safe dialysis access services added to their burden of disease. Treatment time was extended due to equipment shortages and equipment malfunctions. P12, a 39-year-old female shopkeeper, described her experience: "*There was a time, not long ago, when the machines were not working properly, and I had to go through that procedure, and during the whole process, we stayed there for six hours as they tried to fix the machines.*" Unpredictability with equipment also adds anxiety and can upset patients' schedules as they cannot plan their treatment time. Missed or incomplete treatments due to equipment failure directly impact infrastructure challenges and their subsequent consequences for treatment adherence and patient outcomes. The quality of dialysis services is achieved through investment in high-quality dialysis equipment and preventive maintenance.

The dialysis machine's inability to operate forced people to undertake trips that yielded no tangible gain and wasted time, as they did not receive the necessary treatment. This was evident in a personal narration by one of the interviewees, P10. P10 was a 47-year-old man and a businessman. He said, "*You may go there, and they tell you that the machine cannot work, or the machine has all been engaged. Come another day.*" *This is a great loss for people living far from urban areas, as travel can be quite expensive and time-consuming.* In addition, there are negative effects associated with such situations, including the rapid deterioration of health.

Other parties reported extreme impacts of equipment failures and power outages. P15 elaborated on the severity: "*One time I had to travel 70 km to reach the hospital for dialysis appointment, on arrival, they told me there is no electric power and the generator is broken, I had to return home without even getting treatment, spent money to no avail, the following day I was very sick as I missed my treatment session, I had to borrow more money to travel back home.*" P16 shared: "The machines sometimes get jammed in the middle of treatment, and they tell you to wait until they can fix it, and then you sit there for hours not knowing if they will be able to get it ready for you or if they will send you home. It is very frightening because you know that your life depends on that machine." P6, a 41-year-old female farmer, observed: "*If the machines are down, I feel helpless, I am not able to understand these medical things, but I know my life depends on the machines.*" The experiences highlight how patient safety and well-being are directly at risk because of deficiencies in the infrastructure, and that this can lead to life-threatening situations when required treatment is not provided.

#### 4.5.2 Boring Nature of Intradialysis Experience

Dialysis was not just physically demanding, but also a mentally distressing process due to the long sessions. The sessions lasted for 4-8 hours, with the participants lying on the machines and being immobilized during the treatment. The longer the treatment lasted, the more the participants' passive role led to boredom. The psychological load is the impact of medical treatment on quality of life, even when it is life-saving, and it imposes a burden of time and loss of autonomy. Intradialysis experience adds to the overall burden of treatment and can have a long-term impact on adherence if unaddressed. Enhancements to the patient environment, entertainment, and peer support during treatment could all help improve patients' experience at facilities.

Patients talked about the psychological challenges of being immobilized for an extended period of time during treatment. P13 noted: *"Just sitting in that chair for 6 hours, sometimes 8 hours sitting, watching the blood go round the machines, it's very boring. You can't really move around very much, can't eat properly, and you just sit there. I try to sleep, but the noises from the machines keep me awake. Some people keep their eyes on their phones, but I get tired.* Participant 14 said: *"When I am at dialysis, the time goes very slowly, but I bring a book to read, but I can't concentrate on it; I am thinking about my problem – money, children, health. There is nothing else to do but to think and worry, and that's really hard emotionally."* Limited physical space and little to no meaningful activities lead to conditions in which patients' thoughts turn inward, and they can be preoccupied with their conditions, which may worsen anxiety and depression. The intradialysis period is a window of opportunity during which structured support interventions would be possible if the necessary resources were in place.

#### 4.6 Theme 3: Financial Constraints

##### 4.6.1 Financial Challenges and Need to Travel

The cost of kidney disease proved to be the most salient and troubling issue across all interviews. The cost of treatment was a persistent concern, with participants reporting it as unaffordable, even with SHA coverage. P7 estimated monthly expenses: "I'm using close to, I can't even approximate it, but if I had to give a figure, I'd talk of like 30 to 40 thousand a month." These costs are almost three times the national average monthly household income of KSh. 13,529, which is a catastrophic health expenditure, quickly depleting family resources. Financial consequences are directly related to employment loss, asset depletion, and dependency themes discussed elsewhere in the findings.

Transportation costs were an ongoing expense, and a major one for rural participants. P1 travels "around 25 kilometers" to get to the dialysis center, and P10 travels "60-70 kilometers". The distances necessitate substantial fuel costs, and sometimes accommodation expenses. Patients already challenged financially by medical expenses also face transportation barriers that can lead to non-adherence. Financial barriers are exacerbated by geographic barriers, especially for the rural population, who are already vulnerable. This burden could be greatly alleviated by providing a new satellite dialysis center in the rural area or by providing transportation subsidies.

Other participants reported the total costs of travel, lodging, and out-of-pocket health expenses. Participant 15 talked about transportation expenses: *“I use more than 3,000 shillings each week on transportation alone. This amounts to 12,000 per month just for hospital travel. There are other medications that are not paid for by SHA, costing an additional 5,000 to 8,000. Plus, the special food prescribed by the doctor, which costs 10,000. How do I raise this money? I don’t have employment.”* Participant 16 explained: *“At times, I am required to remain near the hospital because dialysis takes too long, and there are no means of getting me back home to the village. I incur accommodation expenses, either 500 or 800 shillings. Additionally, I need to cater to food expenses for two days. All these things add up. My relatives have sold three goats so far to settle these extra charges.”* The narratives clearly highlight the importance of dialysis procedure insurance coverage; however, they also note high out-of-pocket costs across various areas.

#### **4.6.2 Work-Life Balance and Implications for Financial Abilities**

The disease obliged many respondents to cut their working hours or even leave their jobs, thus entering a destructive cycle in which their expenses increased while their incomes dropped significantly. Respondent P5, who used to be a physiotherapist, stated, *“I could not work. Thus, I saw my income declining.”* Employment issues were prevalent, occurring among 13 of the 16 participants (81%). The rise in healthcare costs, coupled with a decline in earning capacity, creates an economic dilemma that will leave families poor, regardless of their financial state before the disease. Employment problems are closely linked to dependency, since former self-supporting individuals become dependent on their relatives.

Business owners faced a unique problem in maintaining their operations while undergoing regular dialysis. P9 spoke of the effect on his hardware business: *“I have to hire somebody, and when I leave, even stuff I could do at home, I need to have a lot of help with.”* The economic losses come not only from having to pay for replacement workers, but also from the owner missing work and from income losses when business operations continue without the owner. This is particularly difficult for self-employed people who lack the employee benefits or sick pay available to salaried employees.

The participants who had financial savings and those who retired saw their resources rapidly deplete. P13 explained: *“I retired with some savings and a pension. I thought this money would last me into old age and help my children, but in two years, it has all been spent. I have little left to invest or save, I fear, for my children are expecting an inheritance and I doubt that they will receive any debts.”* P14 shared: *“I had a great hair salon, my clients were sweet, I couldn’t stand for long periods of time, I couldn’t go to work on dialysis days, the following day would be too weak to work, and I lost the majority of my clients as well. I don’t know how we are going to get by now, because my rent is over, my school is pending, you have no idea how little profit I get.”* These examples show how ESRD reduces current incomes and undermines future financial stability.

## 5. Discussion

### 5.1 Financial Burden and Access Challenges

The findings of this study established that financial burden was one of the greatest challenges faced by patients undergoing maintenance hemodialysis. Participants reported high treatment-related expenses, transport costs, and loss of income due to reduced ability to work. These findings are consistent with Japiong et al. (2023), who found that financial difficulties significantly reduced dialysis adequacy due to the inability to maintain recommended treatment frequency. Similarly, Dada et al. (2019) reported that financial constraints in Nigeria led many patients to reduce the number of dialysis sessions, increasing the risk of adverse health outcomes. The findings also align with studies across sub-Saharan Africa showing that the high cost of dialysis contributes to catastrophic health expenditure and treatment non-adherence among patients with ESRD (Japiong et al., 2023).

The study further revealed that rural participants faced significant transportation challenges due to the long distances to dialysis centers. These findings support studies from sub-Saharan Africa, which identified geographic inequities and poor access to dialysis services in rural areas as major barriers to treatment adherence and quality care (Tadesse et al., 2021; Furia et al., 2019).

### 5.2 Psychological Impact and Coping Mechanisms

The study found that patients experienced anxiety, depression, altered body image, sleep disturbances, and emotional distress associated with lifelong dialysis treatment. These findings are consistent with Sallam et al. (2022), who reported a high prevalence of depression among hemodialysis patients, and Al-Ali et al. (2021), who documented widespread sleep disturbances among dialysis patients. The findings also align with those of Malfasari et al. (2023), who found that body image concerns are common among patients undergoing hemodialysis.

Religious faith emerged as the major coping mechanism among participants. Similar findings were reported by Tadesse et al. (2021), who found that spiritual beliefs and religious support are important coping strategies among dialysis patients in sub-Saharan Africa. The study therefore demonstrates the importance of integrating psychosocial and spiritual support into routine dialysis care.

### 5.3 Healthcare System Challenges

The study findings revealed that machine breakdowns, equipment shortages, power interruptions, and limited dialysis infrastructure negatively affected patient experiences and continuity of care. These findings are consistent with Maritim et al. (2022), who reported limited access to adequate renal replacement therapy across sub-Saharan Africa. Similarly, Ashu et al. (2022) established that dialysis access remains extremely low in most African countries due to inadequate infrastructure and limited healthcare resources.

The findings further showed that rural patients faced additional barriers due to centralized dialysis services concentrated in urban areas. This aligns with studies conducted in Ethiopia and Tanzania, which found that urban concentration of dialysis facilities contributes to treatment inequities among rural populations (Tadesse et al., 2021; Furia et al., 2019).

## 6. Conclusion

This study established that maintenance hemodialysis profoundly affects the lives of patients with End-Stage Renal Disease (ESRD) in Machakos County, Kenya. The findings revealed that patients experience major disruptions in their physical, psychological, social, and economic well-being. Participants described living with constant fear of poor health outcomes, lifelong dependence on dialysis, restrictions in social participation, fatigue, altered life plans, and psychological distress such as anxiety, depression, and hopelessness. The study further found that dietary and fluid restrictions, sleep disturbances, and altered body image negatively affected their quality of life and everyday functioning.

The study also established that patients face significant challenges in coping with maintenance hemodialysis. These challenges included machine breakdowns, long and emotionally draining dialysis sessions, high treatment and transportation costs, loss of employment and income, and increasing dependence on family members for financial and emotional support. Participants adopted various coping mechanisms, such as family support, faith, personal resilience, and adjustments to daily routines; however, these strategies were often insufficient to address the overwhelming burden of the disease.

## 7. Recommendations

There is a need to expand healthcare coverage for dialysis-related medications, nutritional supplements, and supportive treatment to reduce the financial burden on patients and improve treatment adherence. County governments should also establish additional satellite dialysis centers in rural areas to improve access to hemodialysis services and reduce patients' transport costs.

Healthcare facilities should adopt a multidisciplinary and patient-centered approach that integrates psychological support services into routine dialysis care due to the high levels of depression and anxiety reported among patients. Family members should also be involved in patient care and education to strengthen emotional support and reduce caregiver strain.

Community-based kidney disease awareness programs should be strengthened through churches and local support systems to promote coping and early health-seeking behavior. In addition, the government should strengthen the prevention and management of diabetes and hypertension at the primary healthcare level to reduce the rising burden of ESRD. Support groups for patients on maintenance hemodialysis should also be established to enhance emotional, social, and psychological support.

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