Original Article

Lived Experiences of Patients Undergoing Hemodialysis in Selected Teaching Hospitals in Rwanda

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Abstract

Background
End-stage renal disease (ESRD) requires hemodialysis (HD) for management. Various impacts of HD on the quality of life (QoL) of patients have been reported elsewhere, but not in Rwanda. We investigated the lived experiences of patients undergoing HD in Rwanda.

Methods
This qualitative study used a phenomenological design involving interviews of 11 patients. The study population was patients undergoing dialysis in renal units at the University Teaching Hospital of Kigali (CHUK) and King Faisal Hospital (KFH), Rwanda. Purposive sampling was used to recruit patients above 18 years who could speak without experiencing any mental or auditory disorder. The data were transcribed, coded, and analyzed through the thematic analysis approach using Atlas.ti.

Results
Patients' lived experiences included physical challenges arising from discomfort and dietary restrictions; emotional challenges before, during, and after HD; psychosocial challenges encountered with peers, community, and caregivers; and health system-related challenges associated with appointment, lack of access to HD service, and logistics, among others. All the reported experiences affected their QoL during their HD treatment.

Conclusion
Rwandan patients undergoing HD experienced various physical, emotional, psychosocial, and health system-related challenges that affect their QoL. Thus, it is important to enhance patients' education on fluid and dietary management, provide comprehensive emotional and psychological support, address logistical barriers to accessing HD services, and support caregivers through counseling and financial assistance.

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Introduction

End-stage renal disease (ESRD), defined by the glomerular filtration rate (GFR) lower than 15 mL/min/1.73 m^2, is a worldwide issue that encompasses several pathological mechanisms underpinning irreversible kidney function impairment.[1] More than 800 million people worldwide (10% of the overall population) have chronic kidney disease (CKD), which is a degenerative disorder. Low- and middle-income nations are particularly burdened by CKD because they are least prepared to handle its effects, thus making CKD one of the major killer diseases in the world. The ESRD requires patients to attend HD sessions for their whole lives. Worldwide, nearly 4 million people are living on renal replacement therapy (RRT), and hemodialysis (HD) remains the commonest form of RRT, accounting for approximately 69% of all RRT and 89% of all dialysis.[2] According to the World Health Organization (WHO), eight million individuals will need dialysis by 2025.[3] It has been reported that the majority of the patients who need RRT are from low-to middle-income countries, but most of them die due to inability to access RRT.[4, 5]

In the United States, the incidence of ESRD in 2018 was reportedly 390.2 per million, while the prevalence was 242 per million. It occurs 3.4 and 1.5 times higher in Black and Hispanic patients, respectively, than the White patients.[6] In a 2019 report from France, 91,875 patients were receiving RRT, with 45% having a functioning kidney transplant and 55% relying on HD.[2] In Iran, by the end of 2016, the number of patients undergoing HD was estimated to be 29,200.[7] Though data on the etiology and burden of ESRD in Africa is scanty due to lack of renal registry in many African countries, recent statistics show that 13.5% of patients receiving RRT are on peritoneal dialysis and 71.8% are on HD.[8] A recent review identified 81 studies across 24 African countries that have published evidence on HD-treated ESRD due to unknown etiology in the last two decades.[9] The study reported high prevalence in Sudan (71.2%), South Africa (45.0%), Morocco (44.2%), Ethiopia (36.7%), Mauritania (36.3%), Ghana (29.0%), Gambia (28.6%), Egypt (28.0%), Somalia (24.4%), and Libya (20.7%), among others. While there is still scarcity of data on the epidemiology of ESRD in Rwanda, there were only about 157 patients who underwent HD at the University Teaching Hospital of Kigali (CHUK) between January 2014 and December 2017, out of which only 64 patients had ESRD.[10] Between September 2020 and July 2021, 96 patients were dialyzed in public facilities in Rwanda, including King Faisal Hospital (KFH, 45), Rwanda Military Hospital (35), CHUK (9), and University Teaching Hospital of Butare (7).[11]

Lived experience refers to an individual's personal and subjective encounters, including emotions, perceptions, preferences, and goals, during a particular life event. It is best explored by a qualitative study, which is a research approach that focuses on gaining in-depth understanding of experiences, perspectives, and meanings through non-numerical data. During a long time of HD treatment, patients face many restrictions and suffer from emotional, physical, financial, spiritual, and life-change problems. Thus, comprehensive treatment for these individuals is necessary to reduce these consequences.[12] Accordingly, carrying out qualitative research to identify the perspectives of patients with ESRD undergoing HD will assist healthcare providers in meeting their needs towards enhancing their QoL. To answer a research question, *"What are the lived experiences of HD patients in Rwanda?"*, this qualitative study investigated the lived experiences of ESRD patients undergoing HD in two popular tertiary hospitals in Rwanda, CHUK and KFH.

Methodology

Study design and setting

This qualitative study used a phenomenological design , which is a study of how things appear to us when we experience them, or how we experience things in general. The study was conducted in the CHUK and KFH renal units. The settings were preferred because the majority of ESRD patients are diagnosed and managed in these hospitals in Rwanda. The CHUK, located in the Nyarugenge district of Kigali, is the largest hospital in Rwanda, with a capacity of 519 beds, providing quality healthcare to the population through different services, including HD. Its HD service started in 2014 with 8 HD machines. The KFH, also located in the Gasabo district of Rwanda, is among the big hospitals with 160 inpatient beds. The hospital has different specialty services, which include HD. The HD unit of this hospital started in 2010 with 9 HDmachines, which have now increased to 20.[11]

Study population and eligibility criteria

In this study, the study population was 78 patients diagnosed with ESRD undergoing HD in the renal units of CHUK and KFH. This study included patients in the sample according to the following inclusion criteria: patients undergoing maintenance HD, patients 18 years old and above, and patients who could speak without experiencing any mental or auditory disorder. This study excluded patients undergoing acute HD, patients less than 18 years old, and patients with mental illness or hearing problems.

Sample size and sampling procedures

This study used a purposive sampling strategy to select participants who were enrolled in key informant interviews. We used a non-probability sampling strategy where samples are selected based on the qualities required by the researchers. Data saturation was reached at 11 participants, including 6 males and 5 females with an age range from 26 to 65 years.

Data collection instruments, procedures, and quality control

The study used a semi-structured interview guide as a data collection tool, which had three sections. The first section covered the demographic characteristics, including age, sex, marital status, education status, occupation, Ubudehe category (household categorization based on their socioeconomic status), year of CKD diagnosis, and year of HD initiation of participants. The second section focused on identifying the physical, psychosocial, and emotional experiences of patients undergoing HD treatment. The third section focused on understanding healthcare systems-associated factors experienced by patients undergoing HD treatment. Meticulous efforts were made to ensure credibility, dependability, confirmability, and transferability of the instrument used in the study. To ensure the reliability of the data collected in this study, a pilot test was conducted on two patients before full-scale data collection. This helped us to identify any issues with the data collection tools or procedures, allowing for adjustments to be made to enhance reliability. Content validity was ensured by conducting a thorough literature review to identify key concepts and themes related to the study's objectives. This helped to ensure that the questionnaire covered all relevant areas. Subject matter experts were consulted to review the questionnaire items, and they provided insights into the adequate coverage of the questionnaire on the aimed concepts. The content validity process ensured that each question is directly related to the research objectives, clear, and unambiguous.

The ESRD patients undergoing HD were interviewed in April 2024, and their interview duration ranged between 25 to 45 minutes. The interviews were audio-recorded, transcribed verbatim, and translated into English by the author for final analysis. An extensive face-to-face interview covering the study's goals was used to enable participants to express their feelings and thoughts. After obtaining ethical clearance from relevant authorities, the record book of patients who were under HD was obtained from the renal nurses in charge of the facility to identify patients with ESRD. Eleven patients who agreed to participate in the study signed the consent form and were consequently interviewed for the study’s data collection.

Data processing, study variables, and statistical analysis

The data were analyzed using a content analysis approach, which describes the visible, obvious components of the data to interpret the data at a minimal level of abstraction to answer the research question. Three levels of coding were used for the data. In level 1 coding, the data were examined line by line, and codes were made from the language of the participants. In level 2 coding, the comparison of the data separately coded by the authors was made. In level 3, a central theme was derived from the categories that emerged during coding. This study used thematic analysis and Atlas.ti Version 9.1.3 to analyze and apply codes and code groups for all qualitative data. Consequently, five themes were generated, including physical discomfort, dietary restrictions, fluid management, emotional struggles, and the impact on QoL. Thereafter, the Query tool and word frequencies were used while analyzing and developing the final report.

Ethical approval and consent to participate

The authors got ethical approval from the Institutional Review Board of the University of Rwanda (CHMS/IRB/066/2024) on 15th January 2024. Following the University's approval, the authors also got a separate IRB approval from KFH (KFH/2024/146/IRB) on 16th February 2024 and CHUK (EC/CHUK/019/2024) on 20th February 2024 before the data collection process, permitting their hospitals and patients to be used for the study after a thorough review of the study's protocols. The respondents were contacted in the renal units, and the authors explained the details about the study, including its objectives, inclusion criteria, and the procedures for the study to enable them to decide if they wished to participate in the study or not. They were informed that participation in the study is voluntary and that their decision to participate or not has no effect on the services they are normally entitled to in the hospital. Their right to withdraw from the studyanytime was also made known to them. The participants signed the consent form following their agreement to participate in the study.

Results

Demographic characteristics of the participants

In this study, the total number of patients who participated was 11: 6 males and 5 females. Their age range was between 26 to 65. Concerning their education, nine participants were educated up to a diploma and below, while 2 had a university education. The duration of their HD was between 1 to 7 years (Table 1).

Table 1. Demographic characteristics of the patients

Characteristics	Categories	Number	Percentage (%)
Sex	Male	6	54.5
	Female	5	45.5
Age	20 to 40	3	27.3
	Above 40	8	72.7
Education	Illiterate	0	0.0
	Primary to diploma	9	81.8
	University	2	18.2
Married status	Single /widow	2	18.2
	Married	8	72.7
	Divorced	1	9.1
Work status	Employees	2	18.2
	Unemployed	9	81.8
Ubudehe (socioeconomic status)	I	1	9.1
	II	2	18.2
	III	8	72.7
Duration of dialysis	1 to 4 years	9	81.8
	4 to 7 years	0	0.0
	7 years and above	2	18.2

Lived experiences of the participants

The findings of this study are divided into 5 themes. Themes I – IV are about the physical, emotional, psychosocial, and health system-related experiences, while Theme V is about the effect of HD on the QoL of the patients (Table 2).

Table 2.Themes and subthemes of the patients' lived experiences

Themes	Subthemes
Physical experiences	Physical discomfort experienced by patients
	Dietary experiences of patients
	Support systems and coping mechanisms
Emotional experiences	Emotional experience before undergoing HD
	Patients' feelings during and after HD sessions
	Resilience and hope for life
Psychosocial experiences	Experience with caregiver and family
	Peer and community relationship experiences
	Financial burden experiences
	Psychosocial challenges faced by patients
Health system-related factors	Appointment experiences
	Barriers related to the availability of HD machines or facilities
	Challenges in accessing HD services
Quality of life	Impact on Quality of Life

Theme 1: Physical experiences of patients undergoing HD

Subtheme 1.1: Physical discomfort experienced by patients undergoing HD

Patients frequently report experiencing substantial physical discomfort during and after their HD sessions. One patient shared,

> *"When I come for dialysis, I feel physical weakness; after the session, I lose more energy with a decrease in appetite and too much weakness" [KII, KFH].*

This recurring theme of post-dialysis fatigue was echoed by others, while they were indicating a common struggle with diminished energy levels, which profoundly impacted their daily activities and QoL. Another prevalent issue was the difficulty in performing physical activities due to the physical strain caused by HD. The inability to engage in physical exercise and the resulting physical weakness contribute to a cycle of reduced physical fitness and overall well-being. One patient noted,

> *"We're not allowed to perform physical exercise, especially due to the fistula that we have in the arm, because the fistula can be damaged" [KII, KFH].*
>
> *"I don't do any sports because my strength is low, but I can come and do dialysis in the evening when I come home because I work in the evening" [KII, CHUK].*

Subtheme 1.2: Dietary experiences of patients undergoing HD

The dietary experiences of patients undergoing HD reveal the significant impact of dietary restrictions and adjustments on their daily lives. These dietary restrictions are crucial for managing their condition, yet they pose considerable challenges, as patients must constantly monitor their intake and avoid foods they once enjoyed. Many patients expressed challenges with adhering to the strict dietary guidelines, particularly the elimination of certain foods high in potassium and phosphorus. One patient shared,

> *"I have been educated on avoidance of anything that can cause complications from our daily meals, such as bananas, many fruits, nuts, things like those" [KII, KFH].*

Another patient said that:

> *"You have to manage and control what you are supposed to eat, and think that if you eat the food that you are not supposed to eat, you will be in bad condition" [KII, CHUK].*

Despite the challenges associated with dietary restrictions, the patients demonstrated understanding that compliance with dietary advice is for their benefit. They also admitted that adherence to the dietary advice led to their overall wellbeing. For instance, a patient said:

> *"It's difficult at first, but when you start practicing and make it your own, it goes well, especially if you don't have other diseases" [KII, CHUK].*

Thus, the educational support from healthcare providers is vital for patients to navigate their dietary restrictions effectively, as it empowers them with information of what to eat and what not to eat, and the consequences of disregarding the dietary restrictions. However, some patients struggle with temptation and occasional non-compliance, as one patient confessed,

> *"Sometimes, you become weak and want to take the restricted food. For me, it is difficult to stop what I ate before, but I have police at home (my children) who stand up and fight with me when I want to eat what I am not allowed to." [KII, KFH].*

The above shows that patients tend to go against the dietary specifications, but with proper monitoring and support from their family members and caregivers, the rate of compliance would be higher. The dietary experience includes fluid intake, and the patients reported discomfort associated with their restriction from fluid loading.

> *"The challenge is that you just can't drink as much as you want. It bothers you, but because you want your life to be stable, you end up avoiding it" [KII, KFH].*

Thus, the burden of managing fluid intake to avoid complications adds to the physical stress, as highlighted by a patient who explained:

> *"If you don't pay attention, you may feel like you have a lot of water in the body and you have shortness of breath" [KII, KFH].*

Subtheme 1.3: Support Systems and Coping Mechanisms

Support from healthcare providers and the development of personal coping mechanisms are crucial for managing fluid restrictions. Patients receive detailed guidance from doctors and nutritionists on how to manage their fluid intake effectively. One patient describes this support,

> *"I tried to follow the recommendation from my doctor, who advised me to measure the quantity of urine per day, and then I had to drink the fluid equal to that" [KII, KFH].*

Additionally, patients develop personal strategies to cope with thirst, such as occupying themselves with activities to distract from the desire to drink.

> *"In my experience, it requires attention, and try to find something to occupy yourself so that you don't think about how thirsty you are" [KII, KFH].*

Theme 2: Emotional experiences of patients undergoing HD

Subtheme 2.1: Emotional experience before undergoing HD

The emotional landscape for patients about to undergo HD in Rwanda is a tumultuous one, characterized by a mix of anxiety, nervousness, adaptation, hopelessness, and fears of social stigma. As these individuals prepare for a life-altering medical procedure, their experiences are marked by significant emotional upheaval and eventual acceptance, albeit with lingering challenges. For many patients, the time before starting HD is fraught with anxiety and nervousness. The uncertainty of the treatment and its implications weigh heavily on their minds. One patient encapsulates this sentiment well, expressing a deep yearning for normalcy and a life free from the constraints of HD:

> *"Emotionally, you wish that you might feel well like others, and you wish to go back to the way you were; you wish you could have the life you had before." [KII, CHUK]*

Similarly, the other patient describes a brief but intense period of nervousness mixed with curiosity about the unknown aspects of HD:

> *"Before dialysis... You may be wondering what could be wrong with dialysis. It makes you a little nervous." [KII, KFH].*

This anxiety is not just about the procedure itself but also about the time commitment it entails. A patient reflects on the dread of spending long hours on the HD machine:

> *"Yes, before dialysis, I felt anxious because I always thought about the time I was going to spend on the machine without doing other things."[KII, CHUK].*

Another patient illustrates how familiarity with the HD process leads to a more stable emotional state:

> *"Before dialysis, I feel happy, and during it, sometimes I feel weak, and after dialysis, I don't have any problems because I am familiar with dialysis, so I take it as my task."[KII, CHUK]*

Yet, the emotional burden of HD is significant and often manifests as feelings of hopelessness and fatigue. The disruption to their normal activities and the persistent sense of being unwell contribute to these emotions. A patient highlights the physical and emotional toll:

> *"There are no normal activities I can perform unless eating and sleeping only. I cannot do any task that requires more effort."[KII, CHUK]*

The constant contemplation of lost time and missed opportunities also weighs heavily on these patients. As described, one patient lamented the hours spent in HD that could have been used for productive activities:

> *"For me, my emotions don't tend to change, but before dialysis, I always think about 4 hours that I am going to do without doing other things. Sometimes I feel like I should be doing something to generate money." [KII, CHUK]*

The fear of social stigma compounds the emotional distress of HD patients. The prospect of being perceived as weak or unloved due to their condition is a significant source of anxiety. A patient expressed this fear poignantly:

> *"When you go to start, you are discouraged and you see that your life is over, you wonder how people will see you as weak, and you think that those who love you will not love you anymore." [KII, KFH]*

Subtheme 2.2: Patients' feelings during and after dialysis sessions

During HD, patients experience a range of emotions, from relief and normalcy to discomfort and frustration. A patient mentioned feeling a sense of normalcy and even enjoyment during the sessions:

> *"When I'm on dialysis, I don't have any fear. I think it's normal." [KII, CHUK].*

This sentiment is echoed by another patient who finds solace in observing others enjoying themselves, which in turn makes them feel good:

> *"My work is often at parties, in hotels, bars..., but when I see others enjoying, I'm enjoying too. Even if I don't take anything like alcohol, I can see people happy, and I feel good too." [KII, CHUK].*

However, the experience is not universally positive. Some patients report discomfort and challenges during HD. For instance, a patient mentioned facing significant problems that led to fear and anxiety:

> *"During the start of HD, I met with problems which led me to have a fear of HD; it took me a long time to cope with dialysis."[KII, KFH]*

Another patient described the discomfort of the lengthy sessions:

> *"During dialysis, you feel that staying for four hours is something that disturbs a person."[KII, KFH]*

After completing a HD session, patients often experience a mix of physical relief and emotional fatigue. The physical benefits of HD are evident, as the patient noted:

> *"After dialysis, you feel something change in your body. The swelling goes away even if you drink a lot of water, it decreases."[KII, KFH].*

This physical improvement brings a sense of relief and happiness to many patients, as one described:

> *"After dialysis, you feel happy, you feel happy that it went well because during dialysis you can face many different problems... but when you finish it well, you feel so happy."[KII, KFH]*

However, the post-dialysis period is also marked by significant fatigue and weakness. The patient captured this sentiment by comparing himself to a "piece of wood blown by the wind" after a session, indicating a profound loss of energy:

> *"When I finish dialysis, I feel like I have less energy, and I feel like a piece of wood blown by the wind. Nothing else." [KII, CHUK]*

Another patient demonstrated this feeling of instability and unhappiness:

> *"Sometimes after dialysis, you feel unstable and unhappy." [KII, KFH]*

Subtheme 2.3: Resilience and hope for life among HD patients

Patients' resilience and hope while undergoing HD at CHUK and KFH in Rwanda revealed a multifaceted landscape of emotional, psychological, and social dynamics. The patients highlighted both the challenges and the sources of strength that they experienced, providing a comprehensive picture of their lived experiences. Patients undergoing HD often encounter severe physical and emotional challenges, which can lead to moments of despair. For instance, one patient recounted the traumatic experience of losing breath and having dangerously high blood pressure, describing it as the hardest time he had gone through:

> *“The hardest time I went through was the day I lost my breath; my blood pressure went up, and I was brought to dialysis like a dead person. Those times were very sad for me, they were not normal times for me, they were bad for me” [KII, KFH].*

Despite the physical and emotional challenges, there is a sense of acceptance and adaptation among long-term patients. One patient, who has been undergoing HD for eleven years, reflected on the positive aspects and her survival:

> *"I have been doing HD for eleven years, and it has helped me, and my life is going well. I don’t forget that many people are no longer there due to financial issues, medications, catheter-related problems, but I am still alive." [KII. KFH].*

Such moments of acute crisis underline the severity of their medical condition and the emotional toll it takes on them. However, the data also underscore that, despite these harrowing experiences, many patients manage to find strength and maintain hope through various means.

A recurring theme is the pivotal role of social support from family, friends, and healthcare providers. One patient expressed that those visits and encouragement from family members during HD sessions were a significant source of motivation and emotional support.

> *“The times that I went through that inspired me are when families were coming to visit me at dialysis, and they encouraged me. When there is no one with you, when you are alone, you become discouraged” [KII, CHUK].*

Similarly, the constant support and advice from doctors and other healthcare providers were frequently mentioned as crucial in helping patients navigate their treatment and maintain hope. For example, a patient shared that advice from doctors and the realization that HD is essential for survival provided the strength to continue:

> *“When you do HD for one year, two years, and you are still alive, it gives you the power to continue. I remember one day I was depressed and felt like avoiding doing HD, but the doctors asked me: Do you want to die? Then they encouraged me to continue doing it” [KII, KFH].*

Moreover, personal resilience and coping mechanisms play a crucial role in sustaining hope and motivation. Many patients emphasized the importance of maintaining a positive mindset and strong moral values. One patient stated that having morals and a positive attitude helped them overcome the difficulties associated with their condition:

> *“Me, how I maintained the strength in my journey is moral, if you have morals, there is nothing that can stop you, nothing can happen to you, that's all. It is always to be with morals.”*

Another patient mentioned that religious faith and prayer were significant sources of strength and comfort:

> *“Aah! I pray, to pray helps me too” [KII, KFH].*

Theme 3: Psychosocial experiences of patients undergoing HD

Subtheme 3.1: Experience with caregiver and family.

The psychosocial experiences of patients undergoing HD in Rwanda, as reflected in their caregiver and family relationships, reveal a complex interplay of emotional support, financial strain, and significant personal sacrifices. Many patients expressed deep appreciation for their primary caregivers, often their spouses, who provide unwavering support despite substantial challenges. For instance, one patient noted:

> *"My caregiver is my wife, who has been with me since the start of this difficult time. I appreciate her because some women leave their husbands due to a chronic disease. For me, I do not face that issue"[KII, KFH].*

This sentiment underscores the critical role of a supportive spouse in managing the burdens of chronic illness, highlighting a profound sense of gratitude for enduring loyalty and care.

However, the emotional toll on caregivers is significant, often leading to feelings of sadness and helplessness. Another patient shared,

> *"My wife always thinks about the end of this life, and she looks like someone who has lost hope" [KII, KFH].*

This statement reflects the pervasive anxiety and emotional distress that can afflict caregivers, who not only manage the physical needs of the patient but also grapple with the emotional and psychological impacts of the illness on their own lives. Caregivers frequently sacrifice their personal activities and professional engagements to provide necessary care, resulting in financial hardships and altered family dynamics. The data reveal that the illness imposes a substantial economic burden, as one patient remarked:

> *"Since my illness, the family has not developed because it was I who worked for the family. Since this sickness, we have become poor, and my wife is too tired due to hard work because she has to continue to help me and maintain my life." [KII, KFH].*

This highlights the broader implications of chronic illness on family well-being, emphasizing the need for comprehensive support systems to alleviate the multifaceted strains faced by both patients and their caregivers.

Subtheme 3.2. Peer and community relationship experiences

The experiences shared by patients undergoing HD in Rwanda paint a complex picture of their social relationships. While some patients find support and connection, others face isolation and stigma.

Several patients described a sense of community and support from friends and family. One patient highlighted the importance of moral support, stating:

> *‘’When they see you with morals, they also have morals and have hope. So life goes on" [KKI, CHUK].*

Even gestures like receiving financial help through mobile money transfers demonstrate compassion within their social circles. The shared experience of HD also fosters new connections with fellow patients, creating a sense of belonging.

Unfortunately, the illness also presents challenges to social connection. The time commitment of HD treatment and the limitations imposed by the illness itself can significantly limit a patient's ability to socialize. Furthermore, some patients reported feeling isolated or ostracized by their communities. The perception of HD as a contagious illness or the fear of being burdened by someone who is sick can lead to social withdrawal by others.

> *“They think more about it, and they think you can contaminate them or you can cause many problems to them, some of them think that you can ask them to help you, etc.*
> *” [KII, CHUK] and also “Eeh, yes, the first effect happens when you live with people, sometimes they are bored, especially*

> *because they think that this person is not getting better" [KII, KFH].*

This social isolation can be particularly painful, as one expressed:

> *"The worst thing is that I look like an isolated person in society" [KII, CHUK]*

Additionally, the financial strain of treatment can create tension within families and friendships.

The quotes also revealed the strain that HD can place on existing relationships. Family members may become tired or overwhelmed by the constant demands of caring for a sick individual. The patient stated:

> *"In general, the family does not know what is in a person; it is the person who knows herself. Where I was before is not where I am now. Maybe my roommate noticed that I was having a hard time. Then we sat together, and he told me that he had cared for me for a long time, and now he was tired of being with me. I accepted it and allowed him to go somewhere else."[KII, CHUK]*

Subtheme 3.3 Financial burden experiences

The quotes from patients undergoing HD in Rwanda paint a clear picture of the significant financial strain this treatment creates. Even with government support covering HD itself, significant out-of-pocket expenses remain, as reported by many patients. Patients struggle to afford transportation, medications, and the specific dietary requirements needed to support their health. One quote poignantly highlights this, stating that:

> *"It is very difficult...because even if the dialysis itself is covered...the food prescription itself is very expensive" [KII, CHUK].*

This financial burden forces patients to make difficult choices, as another quote reveals:

> *"There are things we have tried to sacrifice in our normal life, such as food, clothing, travel" [KII, KFH].*

The HD treatment schedules and the limitations imposed by the illness often prevent patients from working. This significantly reduces household income, as mentioned here:

> *"We have lost the ability to work, that is why we have poverty at home" [KII, KFH].*

The financial burden is even more severe for those without insurance. Quotes like the following emphasize this point:

> *"You know if I didn't get insurance, it wouldn't be possible".*

These patients may face the impossible choice of forgoing HD or selling their belongings to cover the cost, as mentioned here:

> *"The homes are destroyed, they sold their plots, they sold their houses, they sold their cars, they sold their farms…" [KII, KFH]*

Subtheme 3.4. Psychosocial challenges faced by patients undergoing HD

The patient's quotes revealed a deep sense of loss of self-confidence, particularly related to their ability to work and fulfill traditional gender roles. One patient expresses this statement:

> *"As I said before, we need to accept ourselves as men at home. When we are on HD, it makes us weak and we are no longer able to do sexual intercourse." [KII, KFH].*

The treatment regimen itself, with its demanding schedule and limitations, can be a source of depression. One quote from the patient highlighted this:

> *"Sometimes I refused to receive phone calls because the people asked me more and I felt so tired, but after a while, I coped with it like an English saying that' after difficult times life goes on" [KII, KFH].*

The HD patients in Rwanda face significant psychosocial challenges, including social isolation, financial strain, depression, and loss of identity, all of which impact their mental well-being. Despite these difficulties, some patients demonstrate resilience, finding support from family and friends and adopting coping strategies to manage their illness.

The high cost of treatment forces patients to make difficult financial decisions, affecting their entire family's well-being. Addressing these issues through psychosocial support and financial assistance could greatly improve their QoL.

Theme 4: Health system-related factors experienced by patients undergoing HD

Subtheme 4.1. Appointment experiences

HD patients have varied experiences with appointment scheduling and wait times. Some reported an efficient system with minimal delays, while others faced long waits and technical issues. Positive feedback includes prompt service and quick resolution of technical problems.

> *"There was one time the HD machines had technical problems, then we moved to another center of HD" (KII CHUK)*

However, data also revealed frustrations with appointment scheduling and wait times. Technical problems with equipment can cause delays. Unreliable appointment times are a particular source of stress, as one patient explains:

> *"The particular challenges I got at ………., they don’t obey the time. For example, you can have a plan of 8 AM and go there, then you can start HD at 2 PM, which disturbs your daily plan"(KII CHUK).*

These long waits can be emotionally draining and disrupt patients' routines.

Disruptions to the schedule had a domino effect. Unforeseen delays made it difficult for patients to manage other aspects of their lives, such as work or childcare, like the patient who stated:

> *“The emotions rise and make you angry. There are times when you feel like giving up on dialysis because sitting for two hours waiting and thinking that the 4 hours of HD while they don’t help you is painful. So it makes you tired and you start dialysis with a lot of fatigue.” [KII, CHUK].*

In the context of already burdensome treatment schedules, these disruptions can be particularly frustrating.

Subtheme 4.2. Barriers related to the availability of HD machines or facilities

Access to functioning HD machines emerges as a critical concern for patients in Rwanda. The data presented a concerning picture of limited machine availability and the negative consequences it has on patients.

Several quotes highlighted the scarcity of machines. Patients reported instances where machine malfunctions forced them to travel to other facilities or even miss treatments entirely, as quoted by the patient who stated:

> *“Eee! Eee like there... it happened, the machines are not functioning, then they sent us to another hospital, it tends to happen more often ..., I don't know if it happens elsewhere” [KII, CHUK].*

The problem appears to be more prevalent in certain hospitals, suggesting an uneven distribution of resources. The lack of available machines has a significant impact on patients' treatment and well-being. Missed treatments due to machine malfunction can lead to a decline in health and increased illness, as mentioned:

> *“I have had it sometimes that HD machines had mechanical problems, then I had one week without treatment, which led me to feel bad and very ill, but after one week the machines were repaired and the treatment was resumed.” [KII, CHUK].*

The uncertainty and extended waits also caused emotional distress and fatigue, making it even harder for patients to tolerate treatment. Some patients reported no issues with machine availability, like:

> *“I didn’t encounter any problems with missing HD machines.” [KII, KFH];*

the prevalence of the problem in the data suggests a critical need for more machines. Patients themselves advocate for an increase in the number of machines to meet the growing demand.

4.3. Challenges in accessing HD services

While some HD patients reported relatively smooth access to treatment, the data revealed several challenges that can make this process difficult.

These challenges can be broadly categorized into issues within the healthcare system itself and broader socio-economic factors. Long waiting times are a significant barrier for some patients. Some patients reported that:

> *“There was somewhere we went for HD, and they gave us a time to start HD, and we had to wait a long time. For example, there was one hospital that gave me an appointment at 7 am, and then I started at 6 pm. At that time, I had met with a problem with transport, tiredness, and so on. So, it was too difficult, and you don’t have a choice.” [KII, KFH]*

Unreliable appointment scheduling made it difficult to plan for transportation and other aspects of daily life. Communication issues with healthcare providers and inconsistent quality of care also added to the frustration. Limited availability of resources, such as the need to travel to other facilities for lab tests, also created additional burdens as quoted herein:

> *“We were asked to seek treatment and do laboratory tests in other hospitals. So it was very difficult before they helped, but now, they have changed it” [KII, KFH].*

It is important to note that some patients report positive experiences within the healthcare system. One patient highlighted the improvements made in recent years, such as centralized HD centers, by stating that:

> *“Now that our country has developed, the dialysis center is available. Maybe in the early days, it was difficult because I remember when I started to get sick in 2006, dialysis was not available, I was doing what is called peritoneal even if my body could not cope with it. I had to undergo HD, and my country and health systems helped me and transferred me to where I received it on time. I appreciate them.” [KII, KFH]*

Theme 5: Effect of dialysis on QoL of patients undergoing HD in Rwanda

Subtheme 5.1: Impact on Quality of Life

Adhering to fluid restrictions significantly impacts patients' QoL, affecting their social activities and daily routines. One patient notes the necessity of avoiding social gatherings to manage fluid intake,

> *"Another thing, you avoid parties, it also bothers you, but you get used to it as the days go by" [KII, KFH].*

This adaptation process requires patients to alter their lifestyles drastically, often leading to feelings of isolation and frustration. Despite these challenges, successful fluid management leads to noticeable health benefits. A patient highlighted this positive outcome,

> *"The impact, as I said, is that it improves your health and you come to dialysis in a stable condition, without respiratory difficulty, and you spend a calm night" [KII, CHUK].*

Despite these challenges, there are instances where patients feel supported and cared for during the process. One patient mentioned the positive impact of medical advice and support:

> *"If you are faced with strange challenges, you tell the doctor who gives you advice, and if the problems continue, he prescribes you medicine that can help you."[KII, KFH]*

Discussion

In this qualitative study, we investigated the lived experiences of ESRD patients undergoing HD at CHUK and KFH, which are among the popular tertiary hospitals in Rwanda. Our findings revealed that patients’ lived experiences include physical challenges arising from discomfort and dietary restrictions; emotional challenges before, during, and after HD; psychosocial challenges encountered with peers, community, and caregivers; and health system-related challenges associated with appointments, lack of access to HD services, and logistics, among others. All the experiences reported by the patients affected their well-being during their HD treatment.

Physically, patients face severe discomfort during and after HD sessions, with fatigue being a predominant issue. This fatigue, which may arise from different factors like dietary and fluid restrictions, and the HD procedure itself, significantly impairs daily activities and QoL. These findings align with recent studies that highlight post-dialysis fatigue as a common concern, substantially affecting patients' physical functioning.[13] Additionally, patients are often restricted in their physical activities due to the need to protect their fistulas, compounding their physical limitations.[14]

Managing fluid and dietary intake presents significant challenges for patients. The constant need to monitor and restrict fluid intake adds to their physical and psychological stress. Similarly, adhering to strict dietary guidelines to avoid complications such as high potassium and phosphorus levels is burdensome. This difficulty in dietary management is well-documented, with recent literature emphasizing the emotional and psychological burden associated with constant dietary vigilance.[15] Such challenges are critical in understanding the comprehensive care needed for HD patients.

Emotionally, patients experience significant anxiety and nervousness, particularly before starting HD. The uncertainty and fear of the unknown contribute to this anxiety, as reflected in patients' longing for their pre-dialysis lives. This emotional distress is consistent with findings[15] that reported high levels of anxiety among patients before initiating HD. However, many patients gradually adapt to their new reality, moving from initial discouragement to a state of acceptance. This journey is marked by a gradual adjustment to the routine of HD, although the emotional burden remains significant.[16]

Support from family and healthcare providers plays a crucial role in managing the emotional challenges associated with HD. Family members often provide significant emotional comfort and motivation during HD sessions. One patient highlighted the importance of family support, noting how visits from family members during HD encouraged him. This aligns with the recent study emphasizing the pivotal role of family support in the emotional well-being of HD patients.[17]Healthcare providers also contribute significantly by offering emotional and medical support, which helps patients maintain a positive outlook and adhere to their treatment regimens.[18]

Personal coping mechanisms are essential for sustaining hope and resilience among HD patients. Many patients rely on a positive mindset and engage in religious practices to cope with their condition. One patient emphasized the importance of moral values and a positive attitude in overcoming difficulties. The role of personal coping strategies is well-supported by recent research, which highlights various coping mechanisms used by patients to manage the emotional burden of HD.[19] These findings underscore the need for holistic care approaches that include psychological support and counseling.

The psychosocial experiences of HD patients are deeply influenced by their relationships with caregivers and the economic burden of treatment. Caregivers, often spouses, provide crucial support but also face significant emotional and financial strain. One patient expressed deep appreciation for his spouse, who has been a consistent source of support despite the hardships. The high levels of stress and emotional burden experienced by caregivers are consistent with findings from the study reported similar challenges faced by caregivers of HD patients.[20] Additionally, the economic burden of HD affects family dynamics and financial stability, necessitating sacrifices from family members.[21]

Study Limitation

The strength of this study lies in exploring the detailed experiences of patients undergoing HD at CHUK and KFH in Rwanda, as participants provided insights, feelings, and perceptions of the disease condition and challenges they face.

One of the weaknesses of this study is that it was limited to only two tertiary hospitals, thereby affecting the generalization of the findings to the entire Rwandan population. Thus, future studies exploring the lived experiences of patients in all hospitals offering HD services are strongly recommended.

Conclusion

In conclusion, patients undergoing HD in Rwanda face profound physical, emotional, and psychological challenges, in addition to health system-related challenges, thereby negatively affecting their QoL. Physically, patients endure significant discomfort, fatigue, and limitations in physical activity, exacerbated by the need to protect fistulas and manage strict dietary and fluid intake. Emotionally, patients navigate anxiety and distress, particularly before starting HD, gradually transitioning to acceptance and resilience with the support of family, healthcare providers, and personal coping mechanisms. The psychosocial dimension highlights the critical role of caregivers, who provide essential support but also experience significant emotional and financial strain. It is, thus, important to enhance patients' education on fluid and dietary management, provide comprehensive emotional and psychological support, and address logistical barriers to accessing HD services. Introducing some interventions like peer support groups, financial aid programs, and integration of psychosocial support into the healthcare services at renal units for patients undergoing HD would greatly improve their lived experiences and enhance their QoL.

A public awareness about the need for societal support for patients with chronic diseases, including those undergoing HD, would reduce stigma and shape a positive public belief that can enhance social support for the patients, thereby mitigating the negative impact of Rwandan cultural factors.

if implemented, the recommendations from this study enhance the quality of healthcare services delivered to patients undergoing HD in Rwanda. It will enable synergy between nephrology caregivers and mental health experts towards improving QoL of HD patients. We recommend a countrywide longitudinal qualitative study to document the lived experience of HD patients across the entire Rwandan hospitals with HD services. A policy-level change that will incorporate mental health services in renal care is also recommended. The involvement of non-governmental organizations in the counselling of HD patients would also add value to their QoL and reduce burden on healthcare providers.

Declarations

Consent for publication

The participants were informed that the study would be published as an M.Sc. dissertation of DU and that the authors would publish the findings in a peer-reviewed journal. They consented to the publication of the study.

Availability of data and material

The corresponding authors would provide information about the raw data for this study upon a reasonable request.

Competing interests

The authors state that there are no conflicts of interest to disclose

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Author contributions

UD, NM, and AIA: Conceptualization, Design, Methodology, Data curation and analysis, Formal analysis, Investigation, and Original Draft Writing; NM and AIA: Supervision, Review, and Editing. IAA: Project administration and Revision of the manuscript. All authors read the manuscript and approved the current version to be published.

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