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Lived Experiences of Patients with End-Stage Kidney Disease on Dialysis at Scottish Livingstone Hospital, Kweneng District, Botswana

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Abstract

End-Stage Kidney Disease (ESKD) is a public health problem with increasing prevalence in Botswana. There is limited evidence on ESKD patients experience in managing the condition. Therefore, this research investigated the lived experiences of ESKD patients undergoing dialysis in Botswana. This study adopted an interpretative phenomenological research design. The research used 16 ESKD patients undergoing dialysis at the Scottish Livingstone Hospital. Semi-structured, audiotaped interviews were used for data collection. Collected data was transcribed and analysed thematically to identify shared patterns related to the participants lived experiences. Thematic analysis yielded themes and sub-themes representing the participants' experiences with ESKD. The themes included: Dialysis as demanding (subthemes: Time Burden, disrupted daily routines, Long Dialysis hours); Dialysis experiences (subthemes: predialysis anxiety, Mixed feelings during dialysis, Post dialysis Exhaustion) and Physical Symptoms (subthemes: Persistent fatigue and weakness, Pain and swelling, Respiratory and Systemic distress) In summary, this study showed ESKD and dialysis to be considerably demanding for the patients. Patients had mixed experiences before, during, and after dialysis. ESKD patients have to battle dialysis symptoms daily, which affect their well-being and quality of life. Based on the findings this study advocates for dialysis centres in Botswana to be increased to enhance treatment access and lower disease burden, more healthcare providers to be trained on renal care that include Patient-centred care to address healthcare disparities and increase treatment access, for ESKD patient support programs to be implemented to help them cope with predialysis anxiety, mixed feelings during dialysis and post dialysis exhaustion also to strengthen and support ESKD social programs. Policies and strategies that lessen ESKD disease burden and improve the quality of life for ESKD patients should be adopted.

Keywords: *Lived experiences, end-stage kidney disease, dialysis patients, hemodialysis*

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1. Introduction

End-Stage Renal Disease (ESRD) is a public health concern, as it affects millions of patients globally (Brauer et al., 2024). ESKD requires renal replacement therapies such as dialysis or transplantation due to the irreversible loss of renal function (Hashmi et al., 2023; Hopkins Medicine, n.d.). ESRD disease burden poses a significant challenge to patients, families, and healthcare systems. ESKD global prevalence in 2021 was estimated to be 10% and is expected to increase due to risk factors such as hypertension and diabetes mellitus (Brauer et al., 2024). ESKD is financially overburdening, as patients incur high treatment costs related to dialysis, kidney transplant, and associated comorbidities (Murdeshwar & Anjum, 2023). Patients from low socioeconomic backgrounds experience considerable challenges in accessing the required treatment attributable to cost-related barriers.

Developing countries, including those in Sub-Saharan Africa, experience an increasing rise in ESKD prevalence, which mirrors ESKD global trends. Botswana experiences an increase in ESKD coupled with other problems such as HIV and hypertension. The ESKD rates in Botswana increase demand for dialysis services and the need for studies examining patient experiences with ESKD and its treatment (Murdeshwar & Anjum, 2023).

Studies have been conducted to examine the lived experiences of ESKD patients. Authors agree that ESKD patients experience challenges that extend beyond the physical demands associated with ESKD (Karunamuni et al., 2021; Social Science & Medicine, 2021; Wolpert et al., 2023). ESKD affects patients' social, mental, and economic well-being (Alzahrani et al., 2023; Beaubien-Souligny et al., 2022). Patients also experience symptom burden such as fatigue and pain, which lowers their quality of life and functioning (Al-Naamani et al., 2024). These challenges point to the need for data from low-resource countries, including Botswana, on the experiences of ESKD patients. Developing countries, including Botswana, struggle with challenges such as technology shortage, unavailability of hemodialysis services, and inadequate healthcare infrastructure, which lead to complex challenges for ESKD patients (Walker et al., 2022). Consequently, studies exploring ESKD patients' experiences should be undertaken to develop targeted interventions to meet their needs (Braun & Clarke, 2006; Creswell & Poth, 2018; Smith & Osborn, 2014). This study bridges the knowledge gap by providing evidence on ESKD patients' lived experiences and contextualizes the findings to Botswana for population-specific interventions to address ESKD in the country.

1.1 Problem Statement

ESKD is a public health concern globally. About 850,000 people die annually globally due to ESKD. ESKD ranks as the 12th leading cause of mortalities worldwide (WHO Global Burden of Disease 2021). Dialysis is the primary treatment modality for ESKD. People in need of dialysis continue to rise globally and regionally (Yusop et al., 2024). Botswana faces the challenge of the rising ESKD rates among its population (Brauer et al., 2024). ESKD burden is particularly concerning in low-resource settings like Botswana, where healthcare

infrastructure and access to specialised treatment, such as dialysis and transplantation, are often limited. This leads to a growing disparity between the number of patients requiring care and the resources available. Resource shortages witnessed in the Botswana healthcare system result in long waiting times for ESKD patients and reduce treatment alternatives for them.

ESKD prevalence in Botswana continues to rise despite treatment advances in chronic disease management. Statistics from Botswana reveal that 2248 new ESKD cases were reported by May 2024, representing an increase of 248 new cases over three months (Ministry of Health Botswana, 2024). The sharp increase necessitates prioritized interventions to improve patient outcomes and lower the number of patients affected by the disease. Statistics from the Scottish Hospital's renal unit also reflect the increasing ESKD prevalence rate in Botswana. For example, 61 patients were already undergoing haemodialysis in August 2023, demonstrating increased prevalence and demand for dialysis services in Botswana. Botswana has limited resources supporting alternative ESKD treatment options, such as a kidney transplant. To date, only 22 kidney transplants have been done in the country, which shows overreliance on dialysis as an ESKD treatment modality (Ministry of Health, Botswana, 2024). However, little is known in the Botswana context about ESKD patients' experiences despite dialysis being the primary treatment in the country.

Challenges in accessing ESKD treatment adversely affect the health outcomes of ESKD patients in Botswana. Patients suffer from increased morbidity and mortality risks. Lack of timely access to ESKD treatment, including dialysis, reduces patients' life expectancy and compromises care quality (Yusop et al.,2024). Scottish Hospital is the leading institution offering dialysis services to ESKD patients in Botswana. However, little is known about the experiences of ESKD patients undergoing dialysis in the facility, as no study has focused on this area to date. This affects the caregiver's ability to offer patient-centered interventions that would optimize outcomes for ESKD patients. Previous studies conducted in Botswana have highlighted the limited evidence on the lived experiences of ESKD, challenges they encounter, and coping with ESKD challenges (Sah et al., 2025; Shahgholian & Yousefi, 2018), hence, informing this study.

1.2 Research Objective

To explore the daily experiences of End-Stage Kidney Disease (ESKD) patients undergoing dialysis at Scottish Livingstone Hospital.

2. Literature Review

2.1 Theoretical Review

The Socio-Ecological Model (Bronfenbrenner, 1979) informed this study. The model guided the exploration of interconnected factors influencing care experiences and health outcomes of ESKD patients. The Socio-Ecological Model posits that multiple-level interactions influence one's well-being. The levels include personal/individual, interpersonal, community, and societal. The individual/personal level is the lowest level where factors, including experiences, coping mechanisms, and challenges, influence care outcomes and experiences. In relation to the study, the individual level included aspects such as patient response to ESKD treatment, challenges encountered, and coping strategies adopted to overcome them.

The Socio-Ecological Model recognizes the interpersonal and community levels encompassing resources such as family and community relationships, support, and access to healthcare. As seen in the interpersonal level, patients interact constantly with their environment, a crucial predictor of their health outcomes. Consequently, individuals within the community, such as friends and family, are important support resources for patients. In relation to the study, ESKD patients relied on family and community support for their emotional support.

The model also considers the community level as the Mesosystem and Exosystem that influence patients' well-being. The community levels combine micro and macrosystem interactions and their influence on patient experiences. In relation to the study, the interaction seen in the availability and access to dialysis treatment was a predictor of positive outcomes in ESKD treatment. Other factors, such as the quality of care, ease of transport to the facility, and community support, were associated with positive ESKD treatment outcomes.

The Socio-Ecological Model considers social constructs such as culture and norms as the broader elements influencing patient experiences with a disease or healthcare services. The assumption from the model is that positive cultural values and beliefs are likely to influence patient experiences and uptake of healthcare services. For example, a negative attitude towards kidney disease was a predictor of social isolation and stigma experiences in this study. Additionally, factors such as healthcare policies, resource availability, and supportive leadership also form the broader elements that could influence patient care experiences. Therefore, these constructs guided this study.

2.2 Empirical Review End-Stage

ESKD patients on dialysis face considerable emotional and physical challenges daily (McKie et al., 2022). The inherent physical demands of dialysis treatment, including persistent and overwhelming fatigue (Al-Naamani et al., 2024), significant physical discomfort, and the constant need to adhere to stringent dietary and fluid restrictions, create substantial difficulties that profoundly impact their ability to engage in everyday activities and maintain a semblance of normalcy (Tong et al., 2009b). Dialysis side effects, such as cramping and nausea, worsen the physical symptoms encountered by ESKD patients.

Dialysis sessions are demanding for the patients. Accordingly, Alzahrani et al. (2023) found that patients fit their schedules to the dialysis sessions. This disrupts their daily routines and lowers the quality of their lives. Similarly, patients spent too much time in dialysis sessions and travelling far distances to access dialysis treatments. These demands alter patients' daily routines and alter their productivity, as seen from job losses, decreased involvement in social activities, and inability to perform family roles as expected.

ESKD treatment changes the patient's normalcy. Chronic kidney disease management requires lifestyle and behavioral changes that can be disruptive for the patients. As a result, patients lose control of self and are prone to social isolation (De La Cuesta-Benjumea et al., 2023). Over time, the risk of emotional problems such as depression, anxiety, and feelings of worthlessness develops among ESKD patients. ESKD patients undergoing dialysis often experience loss of independence. Often, they rely on others to meet their daily needs and those related to ESKD treatment. The dependence on others makes them vulnerable, ashamed, and hopeless about

their future. (De Assis Mello & Angelo, n.d.). Therefore, holistic care interventions that extend beyond the biomedical model of ESKD treatment should be adopted.

3. Methodology

An inductive interpretative phenomenological research design was used in this study. It was appropriate as it enabled an in-depth exploration of the study participants' experiences. The research was conducted at Scottish Livingstone Hospital. The hospital is located in Kweneng District, Botswana. It is a 350-bed capacity and a government-funded hospital. The hospital serves the Botswana population, estimated to be 387,983 as per the 2022 census. The hospital has a renal unit with 14 haemodialysis machines. A purposive sampling approach was adopted for study participant selection. 16 participants were recruited for the study. Data saturation guided sample size determination. Semi-structured interview guides were used in this study, and interviews lasting between 30 and 40 minutes were conducted with the study participants. Interviews were done between April and May 2025. The interviews were audiotaped and transcribed verbatim. Setswana was the initial language used in the interviews, followed by translating the data into English language by a qualified translator. Credibility, dependability, transferability, and confirmability strategies were used to ensure rigor& trustworthiness of the study.

4. Results and discussion

4.1 Socio-Demographic Characteristics

Table 1 presents the participants' characteristics. Sixteen participants were included in this study. The sample comprised a higher representation of males (56,3%) than females (43.8%). The ages of the participants varied widely, ranging from 21 to 80 years. Many participants had attained tertiary education, indicating a relatively high level of educational attainment. Of the participants, 43.8% were unemployed, while most ESKD participants had hypertension (43.8%).

Table 1: Participants' Demographics

Variable	Category	n	%
Gender	Male	9	56.25
	Female	7	43.75
Age	21–30	1	6.25
	31–40	2	12.5
	41–50	4	25
	51–60	4	25
	61–70	4	25
	71–80	1	6.25

Marital Status	Single	8	50
	Married	6	37.5
	Widowed	2	12.5
Educational Background	None	2	12.5
	Primary	5	31.25
	Secondary	2	12.5
	Tertiary	7	43.75
Occupation	Farmer	1	6.25
	Civil servant	3	18.75
	Unemployed	7	43.75
	Other	5	31.25
Co-morbidities	Hypertension	7	43.75
	Diabetes Mellitus	4	25
	Other	5	31.25
Length of Dialysis	1 to <2 years	4	25
	2 to <3 years	1	6.25
	3 to <4 years	1	6.25
	4 to <5 years	1	6.25
	5 to <6 years	4	25
	6 to <7 years	1	6.25
	7 to <8 years	1	6.25
	≥8 years	3	18.75

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4.2 Thematic Findings

Table 2: Summary of themes, Sub-Themes, and Participant quotes

Aim	Theme	Sub-theme	Quote
Experiences of ESKD patients	1.Dialysis as demanding	Time and Transport Burden	*"I usually wake up at 5 am feeling tired. I have to arrange transport to the hospital, which is expensive."* Patient 014
		Disrupted daily routines	*At work they expect me to be on duty, while I need to be here*…Patient10
		Long dialysis hours	*The dialysis session itself is long and boring*… Patient 15
	2.Dialysis experiences	Predialysis anxiety	*I often feel anxious and worried about what I will experience during the session (dialysis)* Patient 13
		Mixed feelings during dialysis	*Physically, I will be fine except for feeling bored in that bed. I will be on my phone during this time or sleep to pass the time* Patient 14 *After dialysis; because I've been inside for a few hours, when I get up, I feel tired, my legs are tired and I need to walk slowly* Patient 003
		Post dialysis exhaustion	*I usually experience extreme fatigue and sleepiness all the time……. I was given some tablets, which have helped."* — Patient 006
	3.Physical Symptoms	Persistent fatigue and weakness	*I have lower back pain and my hands and legs hurt so much…. I have severe leg swelling* Patient 004
		Pain and swelling	*I no longer pass urine at all….shortness of breath is the other issue, especially when I drink too much water* Patient 007
		Respiratory and systemic distress	

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4.2.1 Theme 1: Dialysis as Demanding

The participants' data showed that dialysis was a highly demanding treatment for ESKD patients. This could be seen in the effort put into ensuring access to dialysis treatment. Participants spent considerable time and financial resources, and were separated from their families as they sought treatment. As a result, some patients noted that their daily schedules revolved around dialysis. These experiences of dialysis as demanding could be seen in the following sub-themes;

Subtheme: Time burden and transport burden

> Patients reported waking up early, often before dawn, to prepare for dialysis sessions and organize transport to the hospital. The early mornings, long travel times, and logistical challenges were common stressors. Patient 007: *"I wake up at 4 am and prepare something to eat before going to the hospital…. I wait for a hired car to pick me up…I come here every day as if I am a hospital employee."*
>
> Patient 009: "*I wake up at 4:30 am …. then walk to the bus stop to catch a taxi to the hospital*.
>
> Patient 14: *"I usually wake up at 5 am feeling tired. I have to arrange transport to the hospital, which is difficult and expensive.*
>
> Patient 12: *"I wake up at 4 am to get ready for dialysis……I am always anxious about whether the session will go well or not."*

Disrupted daily routines

Many participants described how dialysis disrupted their normal routines. They often have to adjust their daily routines to accommodate their dialysis treatment, making it hard to plan or maintain a sense of normalcy. Patient 007 *"Dialysis affects my daily schedule because, my job is to be here, when I leave from here, I can't go anywhere or do anything, I will be tired, when I get home, I just have to rest… I was a farmer. I would be in the fields, I would be farming and selling the produce on the streets, I would be earning something."*

Patient 008 *"sometimes I plan to do some other things, and I fail because I have to come here(for dialysis) instead. Attending village occasions and gatherings is a challenge; some people end up neglecting you in revenge because they think you are not attending their gatherings intentionally*

Patient 10 *"At work, they expect me to be on duty, while I need to be here" (at dialysis)*

Subtheme: Long dialysis hours

The lengthy duration of dialysis was tiring and significantly limited them to engage in meaningful activities. *The dialysis session itself is long and boring*… Patient 15

Patient 007: *"It's tiring, four hours on the machine is a long time, I get tired when I am here…"*

Patient 12, *It is time-consuming and boring at the same time. I just have to scroll on my phone or sleep throughout the session. Again, three sessions in a week are a lot. Even if I'm working, I feel my purpose in life is to get to another dialysis session*.

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Patient16 *"coming here three times a week to spend four hours on the machine is the most exhausting, but what can I do"*

Despite the above demands, most study participants expressed positive experiences and were hopeful about dialysis treatment. The participants were happy that dialysis improved their health by preventing worrisome symptoms associated with ESKD. One participant, Patient 10, narrated, *"Dialysis has helped me a lot. I used to suffocate and faint before starting treatment. I no longer experience these problems."* Patient 16 expressed similar views. He narrated, "*The treatment (dialysis) is keeping me alive…despite being required to come here three times weekly, which is exhausting."* Similarly, Patient 004 noted that dialysis was lengthening his life despite it being demanding. He expressed, *"it (dialysis) helps prolong our lives…… if you don't dialyze, you will suffer complications such as suffocation and possible death."*

4.2.2 Theme 2: Dialysis Experiences

Participants had mixed feelings of their dialysis experiences. Some participants reported anxiety, while others had physical symptoms during dialysis. Their experiences were classified into before, during, and after dialysis as seen in the following subthemes:

Subtheme: Predialysis Anxiety

Anxiety and uncertainty before dialysis were evident in the participants' narratives. Patients expressed worries about dialysis and its likely complications, as seen in the narratives below.

Patient 13: "*I often feel anxious and worried about what I will experience during the session (dialysis)."*

Patient 15: *"I feel a bit apprehensive, but I try to remain calm before dialysis."*

Patient 11: *"I have anxiety about how dialysis will go before it starts. I sometimes come with swollen legs and face, and difficulty in breathing."*

Patient 001 shared, *"At times, I am scared of the thought that I will be undergoing dialysis. But I have accepted it."*

Sub-theme: Mixed Feelings During Dialysis

Some participants reported mixed feelings during dialysis. In some participants, relief was common, while others expressed pain, discomfort, or feeling bored during dialysis, as seen in the narratives below.

Patient 12: *"Physically, I will be fine except for feeling bored in that bed. I will be on my phone during this time or sleep to pass the time."*

Patient 14: *"I sometimes feel better, but other times I feel worse, with headaches and nausea."*

Patient 001: *"I feel pain when in the machine."* ……*"I would feel better from the shortness of breath during dialysis."*

Sub-theme: Post-Dialysis Exhaustion

Fatigue was a common complaint participants reported after dialysis. This can be seen in the following narratives:

Patient 14: *"I feel completely wiped out after dialysis. It takes me a while to feel somewhat normal again."*

Patient 13: *"I am usually very tired, weak, and sometimes have headaches after dialysis."*

Patient 003 *"After dialysis, because I've been inside for a few hours, when I get up, I feel tired, my legs are tired, and I need to walk slowly.*"

Patient 12 "*After dialysis, I will be exhausted and need to relax a bit before I go to work."*

Patient 15 ". *After dialysis, I feel drained and exhausted. It takes me a while to recover.*"

4.2.3 Theme 3: Physical Symptoms

Study participants experienced different ESKD symptoms regularly. The symptoms included fatigue, difficulty breathing, low urine output, and limb swelling. The participants required regular dialysis sessions to prevent these symptoms and improve their overall well-being. Physical symptoms experienced by the study participants could be seen in the following subthemes:

Subtheme: Persistent Fatigue and Weakness

Most participants reported chronic fatigue and general body weakness. This affected their independence as they lacked the strength to perform their daily activities.

Patient 006 said, *"I usually experience extreme fatigue and sleepiness all the time…... I was given some tablets, which have helped."* Patient 14 added, *"I usually experience severe fatigue, body weakness, headaches, nausea and vomiting, leg swelling, and difficulty in breathing and sleeping."* Similarly, Patient 13 shared, *"I experience fatigue, weakness, leg swelling, frequent headaches, itchy skin, and trouble sleeping."*

Subtheme: Pain and swelling

Participants described pain and swelling as distressing and limiting. They showed to have emotional implications contributing to anxiety, depression, and decreased overall well-being. Patient 004 stated, *"I have lower back pain, and my hands and legs hurt so much. I cannot walk or carry anything. Sometimes people carry me when I have severe leg swelling."*

Patient 003: *"I am always in pain because of kidney disease."*

Patient 002: *"All of my body has problems since being diagnosed with kidney disease. My waist hurt, headaches, and blindness, which started following dialysis."*

Patient 14: *"I usually experience severe fatigue, body weakness, headaches, nausea and vomiting, leg swelling, and difficulty in breathing and sleeping."*

Sub-theme: Respiratory and Systemic Distress

Participants expressed respiratory and systemic complaints, including shortness of breath, limb swelling, and low urine output. The complaints are evident in the following narratives:

Patient 007: *"I do not pass urine at all. I also experience shortness of breath, especially when I drink too much water."*

Patient 12: *"I produce very little urine…I also have swollen legs and, at times, abdomen. I am tired most of the time, feel cramps, and have elevated blood pressure."*

4.3. Discussion

Our goal was to understand the day-to-day reality of patients with ESKD. What we found is that their lives are fundamentally defined by a difficult contradiction: the dialysis machine is what keeps them alive, but the process of getting the treatment feels like an overwhelming, all-consuming burden.

Participants expressed dialysis as demanding in terms of resources, such as time and finances. ESKD patients were separated from their families as they moved closer to the treatment centers. These challenges are seen in other research where patients travel long distances to dialysis centers. ESKD patients in South Africa travel forcefully commute 112.3km to dialysis centers, making dialysis demanding, as evident in Botswana (Japiong et al., 2023). ESKD patients being forced to relocate close to dialysis hospitals is also evident in other studies (Ashu et al., 2022; McDonald et al., 2023). This difficulty is widely reported in resource-constrained settings, including the lived experiences of patients in Rwanda (Uwiragiye et al., 2025) and village-based patients in Pakistan (Akhtar et al., 2024), agreeing with the study findings that dialysis is demanding for patients in Botswana.

Patients expressed a range of physical symptoms, including fatigue, shortness of breath, decreased urine production, and lower limb edema. Patients battled these physical symptoms daily, affecting their health and well-being. Previous research have reported patients experiencing physical symptoms such as fatigue, pain, shortness of breath, and fluid volume excess evidenced by body edema (Al-Naamani et al., 2024; Chaiviboontham et al., 2020). Study participants expressed mixed experiences before, during, and after dialysis. Most patients experienced distressing ESKD symptoms before dialysis, boredom, pain, and fatigue during dialysis, and feeling better, cramps, and fatigued after dialysis. Patients in the study by Almutary et al. (2023) experienced fatigue during and after dialysis, which increased the need for fatigue self-management for them and their families. Sentiment analysis of patient discourse online confirms that patients frequently articulate feelings of distress, worry, and fear regarding their treatment (Shankar et al., 2025). Other studies have reported patients experiencing pain, worries about fistula integrity, a cyclic pattern of dialysis dependence, boredom, and improved symptoms before, during, and after dialysis (Alsing et al., 2022; Appiah et al., 2022).

5. Conclusion

In summary, this study showed ESKD and dialysis to be considerably demanding for the patients. Patients had mixed experiences before, during, and after dialysis. ESKD patients have to battle dialysis symptoms daily, which affect their well-being and quality of life. The study provides evidence that there is a need for comprehensive care beyond the medical aspect of dialysis to address their social and psychological challenges.

6. Recommendations

Based on the findings this study advocates for dialysis centres in Botswana to be increased to enhance treatment access and lower disease burden, more healthcare providers to be trained on renal care that include Patient-centred care to address healthcare disparities and increase treatment access, for ESKD patient support programs to be implemented to help them cope with predialysis anxiety, mixed feelings during dialysis and post dialysis exhaustion also to

strengthen and support ESKD social programs. Policies and strategies that lessen ESKD disease burden and improve the quality of life for ESKD patients should be adopted.

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