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Original Article

Lived Experiences of Kidney Transplant Patients at Selected Referral Hospital in Rwanda: A phenomenological Study

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Abstract

Introduction
Kidney transplantation is the preferred treatment for end-stage renal disease, offering better survival and quality of life than dialysis. However, patients must manage lifelong medication, follow-up, and lifestyle adjustments. While post-transplant experiences are well documented in high-income countries, little is known about kidney transplant patients in Rwanda. Understanding the experiences of patients who received transplants abroad is important. This study explored the lived experiences of kidney transplant patients attending follow-up care at a referral hospital in Rwanda.

Methods
A qualitative descriptive phenomenological study was conducted at King Faisal Hospital, Rwanda. Thirteen purposively patients participated in interviews between March 21 and April 17, 2023. Data were analyzed using descriptive phenomenological thematic analysis. Ethical approval and informed consent were obtained.

Results
Five themes emerged: improved quality of life, emotional challenges, medical management, healthcare system challenges, and cross-cultural challenges. Participants reported systemic gaps, including a shortage of specialists, expensive tests, limited support services, and cross-cultural barriers when treated abroad.

Conclusion
Although transplantation improves health and quality of life, recipients continue to face clinical, psychosocial, and financial challenges. Findings highlight the need for holistic, culturally sensitive post-transplant care and strengthened financial support to improve long-term outcomes.

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Keywords: Lived experiences, kidney transplantation, nephrology, Rwanda

Introduction

End-stage renal disease (ESRD) is a significant health issue worldwide. The total number of individuals with chronic kidney disease (CKD), acute kidney injury (AKI), and those on renal replacement therapy (RRT) exceeds 850 million globally.[1] The prevalence of CKD in Africa is estimated at 15.8% for stages 1–5 and 4.6% for stages 3–5.[2] While specific projections for Rwanda are limited, the annual increase in the incidence of ESRD in similar contexts has been estimated to be as high as 8%.[3] ESRD develops when the glomerular filtration rate drops below 15 ml/min, requiring RRTs like hemodialysis, peritoneal dialysis, or kidney transplantation.[3]

Kidney transplantation is viewed as the best treatment for ESRD because it improves quality of life, restores fertility, eliminates dependence on dialysis, and is more affordable, estimated at about one-fifth of what dialysis does annually.[4] Despite these advantages, patients encounter ongoing challenges, including frequent medical checkups, strict medication schedules, infection prevention, and lifestyle changes.[5,6]

International studies indicate that the experiences after a transplant are greatly influenced by personal and social factors. Patients in the UK highlighted the stark differences in their lives before and after the transplant, moving from fatigue and dependence to better daily functioning, while also feeling a sense of obligation toward their donor.[5] In Denmark and Iran, recipients expressed renewed hope and energy but also worries about graft survival, the risk of returning to dialysis, and the ongoing demands of immunosuppressive therapy.[6, 7] Similar observations in Pakistan indicated that family and social support play a crucial role in coping, adherence, and satisfaction.[8]

However, there is limited information about the experiences of kidney transplant patients in sub-Saharan Africa, where only a few countries have active transplant programs.[9] Despite the increasing number of kidney transplant patients in Rwanda, limited research has explored their lived experiences in the local context. Understanding their quality of life and the challenges they encounter after transplantation is essential for improving post-transplant care and support services.

Specifically, this study seeks to answer the following research question: What are the experiences related to quality of life and the challenges faced by kidney transplant recipients in Rwanda following renal transplantation? Therefore, this study aims to investigate the lived experiences of kidney transplant recipients in Rwanda to better guide patient-centered care, support services, and national renal health policy.

Methods

Study design

This study employed a qualitative descriptive phenomenological design to explore the lived experiences of kidney transplant recipients. Phenomenology was chosen because it focuses on understanding individuals' subjective experiences and the meanings they assign to significant life events, such as undergoing kidney transplantation.[10] This approach was therefore appropriate for gaining an in-depth understanding of patients' perspectives to inform improvements in healthcare and support services.

Study setting

The study was conducted at King Faisal Hospital in Rwanda, a specialized national hospital managed by the government. During the time of data collection, the hospital referred patients abroad for kidney transplantation via the national referral board and then came back for follow-up in Rwanda. The estimated number of patients who underwent kidney transplantation was ten annually since 1999. This hospital provides specialized staff, medicines, laboratory facilities, and follow-up facilities; additionally, it provides services related to early detection of allograft issues through imaging and immunosuppressant drug management.

Study population

This study involved kidney transplant patients receiving post-transplant follow-up care at King Faisal Hospital, Rwanda. The patients considered are those recorded from 1999, when the first patient was sent abroad for a kidney transplant, up to February 2023, as the study started in March 2023. A total of 97 kidney transplant recipients were obtained in collaboration with the renal nurse unit manager from their recording database. From this population, 35 kidney transplant patients met the study's inclusion criteria.

Inclusion and exclusion criteria

Participants eligible for this study were post–kidney transplant patients attending follow-up at the nephrology unit of King Faisal Hospital (KFH) from 1999 to February 2023. To be included, participants had to be aged 18 years or older, able to communicate verbally in either Kinyarwanda or English, mentally stable, capable of providing informed consent, and willing to participate in the study. Patients were excluded if they were diagnosed with kidney rejection at the time of the study, were unable to communicate verbally, were mentally unstable, declined to provide consent, or were younger than 18 years of age.

Sampling method

Purposive sampling, which is defined as the procedure used to select and to interview participants so that the researcher is sure that they have been experiencing the event or phenomenon of interest, was used in this study.[11]

Sample size

The study sample consisted of 13 participants, determined based on the principle of data saturation. According to Polit and Beck, data saturation occurs when a qualitative study has collected sufficient information to fully address the research questions, such that additional data only yield repetitive or duplicate information.[12]

Study instrument and pilot test

Data were collected using an open-ended, semi-structured interview guide that was developed based on an extensive review of existing literature and was pilot-tested with two patients who did not participate in the main study to ensure clarity and relevance. The tool was composed of 2 sections, with section A asking about sociodemographic data and section B asking items related to patients' experience. The guide was initially written in English and later translated into Kinyarwanda to facilitate the interview with patients.

Data collection procedure

Data were collected through in-depth, face-to-face interviews to allow participants to fully express their feelings and opinions related to the study objectives. A list of kidney transplant patients attending follow-up was obtained from the renal nurse unit manager after securing ethical approval from the relevant authorities. Participants who were eligible to participate were identified, and their phone numbers were obtained from the King Faisal call center unit. The researcher provided a brief explanation of the study objectives and allowed participants to choose whether to participate voluntarily.

Interviews were conducted in a private setting to ensure comfort and confidentiality. For five participants whose interviews were conducted at King Faisal Hospital, they were held in a separate room within the internal medicine ward, while eight interviews were conducted in participants' living homes at their convenient time. Signs indicating "Do Not Disturb" were placed outside the interview rooms. During interviews, the researcher used probing and prompting techniques to encourage detailed responses, and conversations were audio-recorded with participants' oral and written consent. Field notes were taken to document nonverbal communication and observations. Each interview lasted approximately 30 to 45 minutes and was conducted in Kinyarwanda. Data were collected from March 21st to April 17th, 2023.

Data analysis

Data were analyzed using a descriptive phenomenological thematic analysis approach to capture the lived experiences of kidney transplant recipients. Phenomenological analysis seeks to describe the essence of participants' experiences, and thematic analysis provides a structured way to identify patterns of meaning across narratives. This approach is consistent with descriptive phenomenological methods described by Colaizzi and Giorgi, where significant statements are organized into themes that reflect the core of participants' experiences.[13]

Recorded interviews were transferred from the recorder to the researcher's personal computer. Transcripts written in Kinyarwanda were translated into English, and each transcript was assigned a participant code like PART 1 – PART 13. The analysis followed a three level coding process. Level 1 coding involved line by line examination of the transcripts by the research team members, generating initial codes grounded in participants' own language. Level 2 coding involved clustering similar codes into categories. JDR and RL coded and categorized the same data, and any discrepancies between them were resolved through discussion and consensus to ensure consistency and dependability. Level 3 coding involved identifying overarching themes from the established categories, reflecting the essential structures of the participants' experiences.

Trustworthiness of the instrument

In qualitative research, ensuring the trustworthiness of findings is essential to demonstrate rigor and reliability. Lincoln and Guba highlighted four key criteria: credibility, dependability, confirmability, and transferability.[14] To enhance credibility, participants were encouraged to share detailed experiences, and findings were verified through discussion and clarification during interviews. Dependability was supported through careful documentation of interview procedures and systematic data analysis, while confirmability was ensured by maintaining an audit trail and engaging a qualitative expert in reviewing the coding and interpretation. Transferability was addressed by providing rich contextual descriptions of participants, the setting, and inclusion/exclusion criteria, allowing readers to judge the applicability of the findings to similar contexts.

Ethical consideration

To gain access to the study settings, permission was granted by the King Faisal Hospital's research committee with approval letter referred to as KFH/2023/054/IRB and the University of Rwanda's (UR) College of Medicine and Health Sciences' internal review board (reference: CMHS/IRB/577/2022). All prospective participants were given the assurance that participation is entirely voluntary and they can withdraw any time without any consequences, which was evidenced by a signed informed consent before participation. Transcripts were stored separately from participants' signed consent forms to maintain anonymity.

Data management

All recorded interviews and transcripts were stored securely on a password-protected computer and in a restricted-access folder to ensure confidentiality. The data will be retained for a period of five years after the completion of the study, in line with institutional and ethical guidelines, after which all digital files, including audio recordings and transcripts, will be permanently deleted. Informed consent hard copies will be torn to prevent unauthorized access.

Results

1.Demographic characteristics of respondents

The study involved 13 participants aged 25-63 years, with a majority living in Kigali City. The participants were mostly married. All patients had different health insurances, which included community-based health insurance, genocide vulnerable fund, Rwanda Social Security Board, Military Medical Insurance, Ministry of Defense, United Africa Partnership, and Ministry of Health.

Table 1. Sociodemographic characteristics (N=13)

Characteristic	Category	Frequency (n)
Gender	Male	10
	Female	3
Age	25-49	9
	50-63	4
Marital status	Single	4
	Married	9
Education status	University	5
	Primary-secondary	8
Profession	Farmer	3
	Public servant	5
	Jobless	5
Socioeconomic status	Category 1[a]	1
	Category 2[b]	3
	Category 3[c]	9
Health insurance status	Insured	13
	Non-Insured	0
Province of residence	Kigali city	9
	Western	3
	Eastern	1

[a] Category 1: The poorest people with no housing, no land, and no ability to feed themselves.

[b] Category 2: Poor households with low-class owned or rented housing but no steady employment, and who could only afford one to two meals per day.

[c] Category 3, self-sufficient households. These include gainfully employed workers, and owners of small/medium enterprises farmers who produced enough to sell at market.

*Category 1: The poorest people with no housing, no land, and no ability to feed themselves. Category 2: Poor households. Those with low-class owned or rented housing but no steady employment and who could only afford one to two meals per day were in Category 3, self-sufficient households. These included gainfully employed workers, owners of small/medium enterprises, or farmers who produced enough to sell at market from the old numerical categories system by Local Administrative Entities Development Agency (LAED) guidelines of 2015–2020.[15]

2. Emerging themes

After analysis of participants' responses, five major themes emerged: (1) improved quality of life; (2) emotional and psychological challenges; (3) financial and treatment burden after transplantation; (4) health system barriers to post-transplant care; and (5) cross-cultural challenges during overseas transplantation. These themes provide insight into the experiences of participants following kidney transplantation. Table 2 summarizes the main themes and their corresponding sub-themes.

Table 2. Summary of main themes and subthemes

Themes	Sub-themes
1. Improved Quality of Life	Happiness and hope
2. Emotional and psychological challenges	Fear of graft rejection
	Workplace frustration and perceived discrimination
	Feelings of guilt toward donors
3. Financial and treatment burden after transplantation	Cost of immunosuppressive medications
	Nutritional and lifestyle adherence challenges
	Transport and access costs
4. Health system barriers to post-transplant care	Shortage of nephrologists
	Cost of medical investigations
	Lack of counseling services
	Limited access to renal nutrition specialists
5. Cross-cultural challenges during overseas transplantation	Unfamiliar food
	Language barriers
	Unfamiliar living environment

Theme 1: Improved quality of life

Most participants expressed gratitude for receiving a kidney transplant, describing it as a turning point that freed them from hemodialysis and the suffering associated with it. Participants reported improvements in physical strength, the ability to drink water normally, and the capacity to resume daily activities such as working, continuing education, marrying, and starting families.

Sub-theme 1: Happiness and hope

Many participants described feelings of happiness, hope, and renewed purpose in life after receiving the transplant. Compared with their previous dependence on hemodialysis, participants reported regaining strength and independence.

One participant explained how the transplant restored his ability to work and care for himself:

> *"Before the transplant, when I was on hemodialysis, I felt weak and incapable of doing anything. Now I feel stronger and able to work again. I am happy and hopeful because I can take care of myself and follow the instructions given after the transplant."* (PART. 1)

Another participant emphasized how the transplant brought back hope and allowed him to participate in important family events:

> *"When I was sick, I was depressed and had no hope for life. After the kidney transplant, I became very happy because it gave me more years to live. I was able to attend my children's weddings, drive myself, and manage my projects."* (PART. 8)

Similarly, another participant described how life continued after transplantation and how it enabled him to achieve personal milestones:

> *"Before the transplant, I felt like I lived in the hospital because I needed dialysis every two days. After receiving the kidney, life continued again. I returned to school, completed university, got married, and now have a child. I work and only visit the hospital for follow-up and medication."* (PART. 4)

Theme 2: Emotional and psychological Challenges

Participants described several emotional challenges following kidney transplantation. These included persistent fear of graft rejection, frustration related to workplace expectations, and feelings of guilt toward their donors.

Sub-theme 1: Fear of graft rejection

Many participants reported ongoing anxiety about the possibility of kidney rejection and the potential need to return to hemodialysis. These fears were often triggered by illness, financial concerns about medication access, or uncertainty about the future.

One participant described the distress experienced when facing health complications:

> *"When I got sick and was told that my kidney was not working well, I started thinking about where I was before the transplant and what if I return to the same life again. I got anxiety, but fortunately I recovered."* (PART. 4)

Another participant explained how uncertainty about long-term medication access created persistent worry:

> "I think about the future of my family if one day the drugs are not available or if disease leads to kidney failure. Such thoughts always come to my mind, although I hope that if I follow the instructions, my kidney will not fail." (PART. 5)

Financial constraints also contributed to anxiety about rejection:

> *"Because the drugs were expensive and not covered by my insurance, I was always worried about missing them. I paid around 200,000 Rwandan francs (~$150 USD) per month without insurance, so sometimes I missed doses and medical follow-ups, which made me worry about kidney rejection."* (PART. 6)

Sub-theme 2: Workplace frustration and perceived discrimination

Some participants described frustration related to employment after transplantation. They reported being treated as physically healthy when assigned demanding tasks but being excluded from opportunities such as promotions due to perceptions that they were medically vulnerable. One participant described the conflicting expectations at the workplace:

> *"Where I work, they sometimes assign me tasks like a normal person because they see me physically stable,*

> *which worries me because it can harm my kidney. At the same time, they do not give me motivation or promotion like other coworkers because they think I am handicapped."* (PART. 1)

Another participant expressed concern that working for others could expose transplant recipients to excessive physical demands:

> *"The government should create support funds for kidney transplant patients so they can start their own businesses. When you work for others, they may give you hard work, but in your own business you can manage yourself accordingly."* (PART. 7)

Sub-theme 3: Feelings of guilt toward donors

Several participants expressed feelings of guilt about the potential risks faced by their organ donors during the transplantation process. Although they were grateful for the opportunity to receive a transplant, they remained concerned about the well-being of their donors.

One participant explained this internal conflict, *"I was very happy and excited about the transplant, but sometimes I thought about my sister, who was going to be operated on even though she was not sick."* (PART. 1)

Another participant described worrying about the surgical risks faced by the donor:

> "*I was happy because I had suffered on hemodialysis, but I kept thinking about my sister's life being at risk. I even tried to make her afraid by asking about anesthesia risks such as dying, but she said she had already decided and was ready."* (PART. 11)

Theme 3: Financial and treatment burden after transplantation

Participants described substantial financial challenges in managing life after kidney transplantation. These included the high cost of medications and medical tests, difficulties maintaining recommended nutrition, and transport expenses associated with accessing specialized care.

Sub-theme 1: Cost of immunosuppressive medications

Many participants reported difficulties affording the lifelong immunosuppressive medications required after transplantation. Financial constraints sometimes resulted in missed doses or irregular follow-up visits.

One participant emphasized that medication costs remained a burden even for those with insurance:

> *"The money for buying medicines is a big issue because they are expensive. Even with RAMA insurance, the 15% co-payment is heavy, especially when you add transport and other medical expenses."* (PART. 11)

Similarly, another participant reported relying on financial assistance to maintain treatment:

> *"The main issue is getting money to buy medicines because I have no insurance. My mother spends more than 230,000 RWF (~$170 USD) monthly. Sometimes she cannot manage to get the money, so I borrow from colleagues to avoid missing doses."* (PART. 10)

Sub-theme 2: Nutritional and lifestyle adherence challenges

Maintaining the recommended post-transplant diet was also reported as difficult due to financial limitations. Several participants explained that the high cost of medical care left little money for purchasing nutritious food.

One participant described these challenges:

> *"For nutrition, it is not easy to follow the recommended diet. If I do not have enough money to buy potatoes, how can I buy apples? Because of financial limitations, I just eat a normal diet."* (PART. 4)

Another participant described similar difficulties despite receiving some government support:

> *"I live in Kigali and receive 50,000 RWF (~ USD 35) per month from government support, but paying rent and other daily needs makes it difficult to afford healthy nutrition.*" (PART. 7)

Sub-theme 3: Transport and access costs

Transport expenses were frequently mentioned as a barrier to regular medical follow-up, particularly for participants living outside Kigali, where specialized nephrology services are located.

One participant explained, *"Even with RSSB insurance, the 15% co-payment plus transport costs is heavy. Sometimes I do medical checkups only once every two or three months because I cannot afford to travel to Kigali regularly."* (PART. 11)

Another participant described the broader financial consequences of repeated medical travel:

> *"My family supports me, but because of the long period of illness from dialysis to transplant in India and buying medicines afterward, we had to sell many valuable things to cover expenses like transport and treatment."* (PART. 6)

Theme 4: Health system barriers to post-transplant care

Participants also highlighted several systemic challenges in accessing post-transplant care in Rwanda. These included shortages of specialized healthcare professionals, high costs of investigations, and limited access to specialized counseling and nutrition services.

Sub-theme 1: Shortage of nephrologists

Several participants reported difficulties accessing specialized nephrology care due to the limited number of nephrologists in the country.

One participant described a concerning experience:

> *"In Rwanda we have very few nephrologists. When you go to emergency, you are treated by doctors who may not be specialized in nephrology, which risks harming the kidney. Once I was admitted with a urinary tract infection and only later discovered the antibiotics prescribed were appropriate for someone with kidney transplant."* (PART. 13)

Another participant highlighted the logistical burden of accessing specialist consultations:

> *"For tacrolimus level testing, I must stay two days in Kigali because consultation is one day and the blood sample is taken the next morning. This requires a lot of money."* (PART. 10)

Sub-theme 2: Cost of medical investigations

Participants also reported difficulties affording routine laboratory monitoring required after transplantation.

One participant explained, *"Without insurance I spend around 100,000 RWF (~$75 USD) for consultation and laboratory tests, which makes it difficult to follow the recommended medical check-ups."* (PART. 6)

Another participant reported occasionally skipping follow-ups due to financial constraints: *"I try to follow the advice given, except sometimes I skip medical follow-ups because of lack of money."* (PART. 12)

Sub-theme 3: Lack of counseling services

Participants emphasized the importance of specialized counseling services to guide transplant recipients in maintaining healthy behaviors after surgery.

One participant described the risks of inadequate education:

> *"Some patients think they are completely cured after transplant and start drinking alcohol or eating excessively. Without proper counseling, this can lead to complications or kidney rejection."* (PART.13)

Sub-theme 4: Limited access to renal nutrition specialists

Participants also reported limited access to renal nutrition specialists, which made it difficult to adjust diets according to changing laboratory results.

One participant explained how nutritional advice improved their health:

"My blood sugar was uncontrolled for a long time until I consulted a private nutritionist who explained how to prepare foods properly. Since then my glucose has been controlled." (PART. 2)

Another participant described the absence of formal nutritional follow-up:

"After the transplant, no one explained the nutritional discipline needed to protect the kidney. I only rely on information from colleagues or what I learned while in India." (PART. 10)

Theme 5: Cross-cultural challenges during overseas transplantation

Ten out of thirteen participants who underwent kidney transplantation in India described several challenges associated with living temporarily in a foreign country. These included unfamiliar food, language barriers, and concerns about environmental hygiene, while the other three did not express such complaints.

Sub-theme 1: Unfamiliar food

Participants reported difficulty adapting to unfamiliar foods and dietary practices during their stay abroad.

One participant described this challenge,

"Because of language problems, we could not order food properly, and they often brought the same very spicy food twice a day." (PART. 7)

Another participant reported difficulty tolerating the local cooking:

"The food was very spicy and unfamiliar, including types of milk and ingredients I had never seen before. This made eating very difficult." (PART. 1)

Sub-theme 2: Language barriers

Communication challenges were commonly reported, particularly at the beginning of the treatment process.

One participant described the experience:

"When the doctor realized that we could not communicate in English, he helped us find a Rwandan person living there who assisted with translation." (PART. 13)

Another participant reported receiving help from acquaintances:

"The main problem in India was the language barrier, but fortunately a friend who lived there helped us communicate until we returned home." (PART. 12)

Sub-theme 3: Unfamiliar living environment

Participants also described concerns about environmental hygiene and infection risk while living in a foreign environment.

One participant explained, *"Doctors warned us not to walk outside the hospital area because of the risk of infection due to poor hygiene in some places."* (PART. 9)

Another participant described their observations: *"Sometimes you could see waste in the streets, which made us worry about infection."* (PART.11)

Discussion

This qualitative phenomenological study aimed to explore the lived experiences of kidney transplant recipients in Rwanda. This discussion interprets these findings by comparing them with existing international literature, organized according to the five major themes that emerged from the data: improved quality of life, emotional and psychological challenges, financial and treatment burden, health system barriers, and cross-cultural challenges. Our findings align with existing literature across multiple contexts, revealing both universal and context-specific challenges.

Improved quality of life

Consistent with the global understanding of kidney transplantation as the optimal treatment for ESRD, most participants in this study expressed profound gratitude for their transplant, describing it as a liberation from the confines of hemodialysis.[4] The return to normalcy encompassing the ability to work, pursue education, marry, and start families was a powerful and recurring narrative. This finding strongly echoes research from the University of Bath in England, where participants described a stark contrast between the fatigue and physical limitations of dialysis and the restored ability to engage fully in life after transplantation.[5] The restoration of hope and the resumption of a life course interrupted by chronic illness, as articulated by our participants (e.g., "life continued again"), is a central, positive outcome that underscores the life-changing potential of the procedure.

Emotional and psychological challenges

Despite the physical recovery, the post-transplant period was fraught with significant emotional and psychological challenges. The most pervasive of these was a persistent fear of graft rejection, a finding that aligns closely with studies from the United States and the United Kingdom.[6,16] In our study, this fear was not merely an abstract concern but was often triggered by tangible stressors, such as intercurrent illness, financial difficulties in affording medication, or the daunting prospect of returning to dialysis. This mirrors the findings of Tucker et al. (2019) in the US, where patients voiced concerns about the length of graft survival and the potential need for another transplant or a return to dialysis.[6]

Participants also reported feelings of guilt towards their living donors, worrying about the surgical risks their healthy relatives had undertaken. This internal conflict, balancing immense gratitude with concern for the donor's well-being, is a well-documented phenomenon. Wiltshire et al. (2021) in the UK noted that recipients often struggle to understand their donor's generosity, and the emotional connection is heavily influenced by the nature of their relationship and the language used around "gift" or "donation".[5]

Furthermore, workplace frustration and perceived discrimination emerged as a unique psychosocial stressor. Participants felt caught in a contradiction: expected to perform physically demanding tasks yet excluded from career advancements due to being perceived as medically vulnerable. This specific form of post-transplant social challenge, while resonating with broader studies on employment changes and stressors,[17] highlights a critical area for advocacy and workplace education in the Rwandan context.

Financial and treatment burden

A dominant theme in this study was the substantial and ongoing financial burden of post-transplant care. The high cost of immunosuppressive medications, even with insurance co-pays, forced some participants to miss doses or delay follow-up visits, directly threatening graft survival. This finding is a stark reminder that thepromise of transplantation as a more "cost-effective" therapy compared to dialysis is only realized if the healthcare system can ensure affordable, long-term access to essential medicines.[4] Our results are highly consistent with international research, such as that from the University of Michigan and Minnesota in the USA, which identified medication costs, treatment burden, and financial difficulties as major determinants of patients' well-being and daily life after transplantation.[6,18]

Beyond medication, the costs of transport to Kigali for specialist care and the challenge of affording a nutritious diet added to the financial strain. As one participant emotionally asked, "If I do not have enough money to buy potatoes, how can I buy apples?" This illustrates how financial toxicity can force patients to make impossible choices between basic needs and medical adherence, a reality also reflected in studies from Iran, where patients' lives are significantly impacted by ongoing expenses and the struggle to return to normalcy.[7]

Health system barriers to post-transplant care

The financial burdens experienced by participants are compounded by systemic gaps within the Rwandan healthcare system. The critical shortage of nephrologists was a major concern, with participants reporting anxiety about receiving non-specialist care in emergencies, which could inadvertently harm their allograft. This logistical burden of care, including the need to travel and stay in Kigali for specific tests like tacrolimus level monitoring, places an undue strain on patients. This finding directly correlates with research from Iran, which revealed that patients often struggle due to inconsistent education and limited knowledge about postoperative care, medications, and emergency support, underscoring a system-wide need for improved patient education and support structures.[19]

Participants also highlighted the lack of accessible renal nutrition specialists and formal counseling services. The reliance on "information from colleagues" or memories from India for dietary guidance, and the observation that inadequate counseling leads some patients to mistakenly believe they are "completely cured," points to a dangerous gap in post-transplant care. This lack of structured, ongoing support can lead to complications and potentially rejection, a risk that has been identified in other qualitative studies.[16,19]

Cross-cultural challenges during overseas transplantation

A unique and significant finding of this study pertains to the experiences of the ten participants who traveled to India for their transplant. The challenges of navigating an unfamiliar culture, from spicy and unfamiliar food to significant language barriers, added a layer of difficulty to an already stressful medical journey. These practical problems, such as being unable to order food correctly or communicate pain effectively, directly impacted their physical recovery and psychological comfort. Some participants reported prolonged admissions due to difficulties with eating, highlighting the tangible health consequences of these cross-cultural barriers.

This finding aligns with research from Pakistan, which demonstrated that coping and adjustment after a transplant are profoundly influenced by one's social and environmental context.[8] For the Rwandan patients, the unfamiliar surroundings and lack of a familiar support system likely amplified feelings of isolation and vulnerability, potentially impacting their overall quality of life during a critical period. The experience underscores the need for pre-transplant counseling that specifically prepares patients and their families for the cultural and logistical realities of seeking treatment abroad.

Strengths and limitations of the study

The study’s qualitative methodology allowed for an in-depth exploration of the lived experiences of kidney transplant recipients, providing insights into how transplantation impacts lifelong allograft survival, physical well-being, and overall quality of life. The use of self-structured, semi-structured interviews ensured that each participant had an equal opportunity to share both positive and negative experiences, capturing a comprehensive view of post-transplant life. Conducting the study at the renal unit of King Faisal Hospital, the only center in Rwanda with specialists for post-transplant follow-up, ensured access to participants with relevant experiences and reliable medical follow-up. However, several limitations should be acknowledged. The study included a small sample from a single site, which may limit the transferability of the findings, although purposive sampling and data saturation were used to enhance credibility. Selection bias may have occurred because participants were identified with the assistance of the unit manager, and patients experiencing graft rejection were not included, potentially limiting the range of experiences captured. As interviews were conducted in Kinyarwanda and translated into English, some nuances may have been lost despite careful translation by bilingual researchers. Conducting interviews in the hospital setting may also have introduced social desirability bias; however, interviews were conducted privately and participants were assured of confidentiality. Finally, due to the small population of transplant recipients in Rwanda, there was a potential risk of identifiability, which was minimized through anonymization and the use of participant codes.

Conclusion and recommendations

This study explored the lived experiences of kidney transplant recipients in Rwanda, revealing improved quality of life alongside emotional, financial, and healthcare-related challenges. As the first qualitative study in Rwanda to document these experiences, it highlights critical gaps in post-transplant care and the healthcare system. These findings underscore the need for coordinated support that addresses medical, financial, social, and psychological needs.

Policymakers and healthcare providers should prioritize accessible post-transplant services, including patient education, counseling, and financial assistance, to optimize adherence and allograft survival. Kidney transplantation offers Rwandan patients a second chance at life, but this opportunity must be supported by a healthcare system that addresses their complex, ongoing needs. With coordinated action across sectors, Rwanda can ensure that all transplant recipients not only survive but thrive.

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Conflict of interest
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Author contributions
Conceptualization, study design, methodology, data collection, formal analysis, and original draft writing were performed by JDR, RL, LR, and DU. EM assisted with data analysis, proofreading, and grammar checking. All authors have read and approved the final manuscript for publication.

References

1. Jager KJ, Kovesdy C, Langham R, et al. A single number for advocacy and communication -worldwide more than 850 million individuals have kidney diseases. *Nephrol Dial Transplant.* 2019;34:1803–1805. doi:10.1093/ndt/gfz174.
2. Kaze AD, Ilori T, Jaar BG, Echouffo-Tcheugui JB. Burden of chronic kidney disease on the African continent: a systematic review and meta-analysis. *BMC Nephrol.* 2018;19:125. doi:10.1186/s12882-018-0930-5.
3. Mukakarangwa CM, Chironda G, Nkurunziza A. Motivators and barriers of adherence to hemodialysis among patients with end-stage renal disease (ESRD) in Rwanda: a qualitative study. *Int J Afr Nurs Sci.* 2020;13:100221. doi:10.1016/j.ijans.2020.100221.
4. Younis HM, Mohammed GT, Khalil SS. Infection control: effect of nursing teaching protocol on nurses' knowledge and practice regarding kidney transplantation patients. *Int J Adv Nurs Stud.* 2018;7:21. doi:10.14419/ijans.v7i1.8711.
5. Wiltshire G, Clarke NJ, Phoenix C, et al. Organ transplant recipients' experiences of physical activity: health, self-care, and transliminality. *Qual Health Res.* 2021;31:385–398. doi:10.1177/1049732320967915.
6. Tucker EL, Smith AR, Daskin MS, et al. Life and expectations post-kidney transplant: a qualitative analysis of patient responses. *BMC Nephrol.* 2019;20:136. doi:10.1186/s12882-019-1368-0.
7. Nielsen C, Clemensen J, Bistrup C, et al. Balancing everyday life: patients' experiences before, during, and four months after kidney transplantation. *Nurs Open.* 2019;6:443–452. doi:10.1002/nop2.225.
8. Kamran F. Living with a kidney transplant: perceptions and experiences. *Am J Appl Psychol.* 2014;2:5–12. doi:10.12691/ajap-2-1-2
9. Kobayashi S, Hidaka S. Can we still ignore renal replacement therapy in sub-Saharan Africa? All living beings are created equal. *Ren Replace Ther.* 2020;6:1–13. doi:10.1186/s41100-019-0243-6.
10. Tavakol M, Sandars J. Twelve tips for using phenomenology as a qualitative research approach in health professions education. *Med Teach.* 2025;47:1441–1446. doi:10.1080/0142159X.2025.2478871.

11. James AF. Reading, understanding, and applying nursing research. 5th ed. *Philadelphia: F.A. Davis Company.*2017.
12. Polit DF, Beck CT. Nursing research: principles and methods. 7th ed. *Philadelphia: Lippincott Williams & Wilkins.* 2003. http://repository.unimus.ac.id/7921/1/2. Beck%2C Cheryl Tatano_ Polit%2C Denise F. - Nursing research_ generating and assessing evidence for nursing practice-Wolters Kluwer Health %282017%29 %281%29.pdf. Accessed 10 March 2025
13. Giorgi A, Giorgi B, Morley J. The descriptive phenomenological psychological method. In: Willig C, Stainton-Rogers W, editors. The SAGE handbook of qualitative research in psychology. 2nd ed. *London: SAGE*; 2017. p.176–192. doi:10.4135/9781526405555.n11.
14. Forero R, Nahidi S, De Costa J, et al. Application of four-dimension criteria to assess rigor of qualitative research in emergency medicine. *BMC Health Serv Res.* 2018;18:120. doi:10.1186/s12913-018-2915-2.
15. Local Administrative Entities Development Agency (LODA). Ubudehe categorization guidelines 2015–2020. *Kigali: Government of Rwanda.* 2015. https://www.loda.gov.rw/updates/news-detail/cabinet-approves-review-and-classification-of-households-into-ubudehe-categories, Accessed 10 March 2026
16. Jones J, Damery S, Allen K, et al. “You have got a foreign body in there”: renal transplantation, unexpected mild-to-moderate distress and patients' support needs: a qualitative study. *BMJ Open.* 2020;10:e035627. doi:10.1136/bmjopen-2019-035627.
17. McKeaveney C, Noble H, Courtney AE, et al. Understanding the holistic experiences of living with a kidney transplant: an interpretative phenomenological study protocol. *BMC Nephrol.* 2020; 21:233. doi:10.1186/s12882-020-01860-3.
18. Lorenz EC, Egginton JS, Stegall MD, et al. Patient experience after kidney transplant: a conceptual framework of treatment burden. *J Patient Rep Outcomes.* 2019;3:8. doi: 10.1186/s41687-019-0095-4
19. Ghadami A, Memarian R, Mohamadi E, et al. Patients' experiences from their received education about the process of kidney transplant: a qualitative study. *Iran J Nurs Midwifery Res.* 2012;17:S157–S164