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Original Article

Understanding the Life and Challenges of Caregivers of Renal Patients Undergoing Dialysis in Kenya: A Qualitative Study

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Keywords:
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The research investigated the multifaceted challenges faced by caregivers of renal patients undergoing dialysis in Kenya, aiming to understand the impact on daily routines, socioeconomic factors, and mental health. Structured interviews were conducted with 32 caregivers (interview conducted till saturation with a target sample size of 59), predominantly spouses and children, revealing a complex web of responsibilities and hardships. The majority of caregivers assumed their roles due to a lack of alternatives, either being the sole available family member or chosen by others. While some experienced disruptions in daily routines, including changes in work schedules and sleep patterns, others adapted by delegating tasks or using financial resources. Caregivers often mirrored the dietary needs of patients, though this posed economic challenges and altered their own eating habits. Economically, caregivers faced heightened living costs attributed to dietary changes, medication expenses, and increased dialysis sessions. The study uncovers a significant decline in the quality of life for caregivers, with financial strains and altered sleep patterns contributing to their overall well-being. Mental health challenges were pervasive, with stress, emotional exhaustion, and even suicidal ideation reported. Caregivers expressed fears of abrupt health deterioration in patients and felt unsupported by medical facilities. The study concludes that caregivers draw motivation from relationships with patients, emphasising the need for comprehensive support mechanisms. The study recommended enhanced support programs, expanded health insurance coverage, and dedicated mental health support and education. These initiatives aim to alleviate the economic burden, improve the affordability of caregiving, and enhance caregivers' mental well-being. Implementing these recommendations ensures caregivers receive the necessary support to navigate their challenging roles effectively, benefiting both caregivers and renal patients.

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INTRODUCTION

The world is currently experiencing an epidemiological transition from communicable diseases to non-communicable diseases (NCDs). Chronic NCDs account for about 74% of global deaths, according to the latest statistics by the World Health Organization (WHO, 2020). Kiragu et al. (2022) reported that more than half (50%) of in-patient hospital admissions and close to 39% of all annual deaths are a result of NCDs. Ammoun et al., (2022) also reported that about 55% of hospital deaths are attributable to NCDs.

Though cardiovascular diseases, cancers, diabetes, mental illness, and chronic respiratory diseases remain the main NCDs, others, too, have grown in prevalence in the recent past. Chronic kidney disease (CKD) is one such condition that is currently reported as a leading cause of morbidity and mortality in both developed and developing countries. Chronic kidney disease (CKD) occurs when the kidney's glomerular filtration rate (GFR) is less than 60 mL/min per 1.73 m² for more than 3 months, with or without kidney damage, or functional or structural renal

abnormalities, with or without reduced GFR. CKD can manifest in five phases, with the most severe phase being end-stage renal disease, which necessitates renal replacement therapy in the form of dialysis or kidney transplantation (Kidney International Supplement, 2013; Webster et al., 2017).

According to a systematic analysis of the Global Burden of Disease Study published in the Lancet Journal, approximately 10% of the world's population was living with CKD by 2015 (Kassebaum et al., 2016). In sub-Saharan Africa, the Global Dialysis Perspective study by Maritim et al. (2022) estimated the prevalence of CKD at 14%. The same study reported a 4% CKD prevalence in Kenya with in-country variations. Chronic kidney disease is increasingly recognised as a major public health in Africa, coming on the heels of a constant rise in risk factors coupled with limited access to renal replacement therapy (RRT) (Kaze et al., 2018). Public health initiatives, including prevention and early detection of CKD, are greatly warranted to keep on track the

achievement of SDG 3 (Good Health and Well-being) target 3.4 on NCDs.

The role of CKD Caregivers and the Challenges They Experience

Family caregivers, according to Eirini & Georgia (2017), are those who are accountable for their patient's care without getting paid. Numerous studies have reported that good family support is profoundly linked to successful patients' adaptation to dialysis treatment and compliance with dietary regimens. However, some patients cease dialysis therapy because they believe they have become a 'burden' on their families. As a result, when appropriate, family caregivers play a crucial role in providing effective communication to dialysis patients (Low *et al.*, 2008). According to Grapsa *et al.*, 2014, caregivers play an important role in the care of haemodialysis patients since many of them have poor physical function and cognitive impairment and are unable to care for themselves. Eirini & Georgia (2017) reported that caregivers provide crucial support, especially in adapting and effectively managing their treatment, helping with household tasks and personal care, managing their funds, and communicating with professional caregivers when appropriate. By the same token, CKD caregivers are involved in facilitation and organising transportation of the patients to dialysis units and other medical appointments such as dietary needs assessments (Suri *et al.*, 2014).

While caregiving can be satisfying and fulfilling, it is reported to be one of the most strenuous and exhausting responsibilities. Indeed, the impact of assuming caregiving responsibilities, especially for patients with chronic illness such as CKD, has been studied by many scholars. According to

Schulz & Beach, 1999; Sherwood *et al.*, 2005; Eirini & Georgia, 2017, caregiving is associated with significant emotional burdens such as depression and a variety of anxiety-related symptoms, overuse of medication, attitudinal shifts in physical health and impairment of quality of life. Schulz & Beach, 1999 reported that caregivers, due to the demanding nature of the job, have a reportedly higher mortality rate than their non-caregiving counterparts. Corroborating the evidence on the impact of caregiving is a study on caregivers of children with complex chronic illnesses, which found that caregiving responsibilities can have a significant impact on the physical and mental health of caregivers. The study highlights the need for clinical practices that prioritise the health and well-being of caregivers in the care of children with chronic illnesses (Álvaro León-Campos *et al.*, 2023). Several scholars, including Gayomali *et al.*, 2008 have recommended that family caregivers should be identified, and their caregiver burden monitored early to optimise their well-being. It is crucial to discuss coping mechanisms that can improve caregivers' quality of life, more so when they are required to provide end-of-life care.

Research Objectives

- To explore the impact of caregiving for renal patients undergoing dialysis on caregivers' daily routines and responsibilities.
- To examine the socioeconomic effects experienced by caregivers of renal patients undergoing dialysis.
- To investigate the mental health challenges and support systems available for caregivers of renal patients undergoing dialysis.

Research Questions

- How does caregiving for renal patients undergoing dialysis affect the daily routines and responsibilities of caregivers?
- What are the socioeconomic effects experienced by caregivers of renal patients undergoing dialysis?
- To investigate the mental health challenges and support systems available for caregivers of renal patients undergoing dialysis.

Significance of the Study

The significance of this study lies in its potential to contribute to both the field of healthcare research and the practical aspects of caregiving for renal patients undergoing dialysis.

- The study addresses a notable gap in the existing literature by focusing on the experiences, challenges, and needs of caregivers of renal patients undergoing dialysis in Kenya. While healthcare research has predominantly centred around the patients themselves, caregivers play an essential role that significantly impacts patients' well-being and treatment outcomes. By exploring the caregiver's perspective, the study enriches the understanding of the holistic care these patients require.
- Renal patients undergoing dialysis often require extensive care and support, which places a considerable burden on their caregivers. Understanding the challenges faced by these caregivers can help healthcare providers and policymakers design targeted interventions and support programs to enhance the quality of care provided to both patients and caregivers. The findings of this study can inform the development of culturally sensitive and context-specific caregiver support services in Kenya.
- Caregivers' physical and emotional well-being can directly impact the patient's overall health and recovery process. By identifying the challenges faced by caregivers, the study can provide insights into potential factors affecting patients' treatment adherence, psychological well-being, and overall health outcomes. This, in turn, can contribute to the development of strategies that promote better patient outcomes.
- The study's findings can inform healthcare policies and resource allocation decisions in Kenya. Understanding the unique challenges faced by caregivers of renal patients undergoing dialysis can lead to policy recommendations aimed at providing targeted support, training, and resources for caregivers. This, in turn, can lead to more effective and sustainable healthcare systems.
- The study can serve as a foundation for future research endeavours in similar contexts or with other medical conditions. By employing qualitative research methods, the study provides a rich understanding of the caregivers' experiences, allowing for the exploration of nuanced factors that might influence caregiving dynamics and outcomes.
- The study has the potential to raise public and healthcare professionals' awareness about the essential role that caregivers play in the lives of renal patients undergoing dialysis. Increased awareness can foster a more empathetic and supportive environment, reducing stigma and facilitating open

conversations about the challenges faced by both patients and caregivers.

Scope and Limitations

Although the study aimed to provide valuable insights into the lives of caregivers of renal patients undergoing dialysis in Kenya, offering a nuanced understanding of their challenges, coping mechanisms, and support needs, there were a number of limitations.

The target population of the study was fifty-nine (59) caregivers actively involved in caring for renal patients undergoing dialysis treatment at Kisumu Specialist Hospital in Kisumu County. These caregivers were family members (such as spouses, children, or siblings) or close friends who were responsible for providing physical, emotional, and logistical support to the renal patients. The interviews were carried out until saturation (32 participants), meaning that potential study participants with useful information could have been left out. The authors used their discretion to declare that saturation has been achieved.

Since the study utilized purposive sampling, selection bias might have been introduced since caregivers who chose to participate in the study may not be representative of all caregivers in Kenya. In addition, the study's findings might have also been influenced by various confounding factors, such as the specific healthcare facilities where the dialysis treatments are administered, the socioeconomic backgrounds of the caregivers, and the availability of support networks, which could impact the transferability of findings to other settings.

LITERATURE REVIEW

Introduction to Caregiver Research in Chronic Illnesses

Numerous studies have explored the impact of caregiving on the daily life and responsibilities of individuals and families who often must provide support for loved ones living with certain diseases or conditions. In the context of chronic conditions, like renal diseases, studies have shown that caregivers grapple with significant disruptions in their daily routines as they navigate the demands of caregiving, potentially affecting their own health and wellbeing (Gayomali *et al.*, 2008; Eirini & Georgia, 2017). Besides, it is noteworthy that caregiving, as reported by existing literature, is characterised by substantial economic implications. Financial strain, career interruption, in addition to altered socio-economic statuses for caregivers, are some of the socio-economic implications associated with taking caregiving responsibilities (Grapsa *et al.*, 2014). Furthermore, caregiving has been linked to heightened mental health challenges, including stress, anxiety, and depression, highlighting the growing body of need to ramp up mental health support interventions and policies aimed at bolstering the mental well-being of caregivers (Suri *et al.*, 2014). By investigating these aspects, the present study contributes to the understanding of the broader societal impact of caregiving for renal patients undergoing dialysis in Kenya.

Understanding caregivers' experiences is significant because they play a crucial role in the management of chronic illnesses in children and adults. Caregiving responsibilities can have a significant impact on the health status of caregivers, including their physical and mental health, as well as their socioeconomic status.

Therefore, it is essential to provide caregivers with solutions to problems, information, and financial and practical help, especially when caring for children with chronic illnesses, which is a complex and demanding undertaking. By understanding caregivers' experiences and providing them with support, healthcare providers can improve patient care and outcomes (Susan & Given, 2013).

The Role and Impact of Caregivers in Renal Patients Undergoing Dialysis

Physical Demands and Challenges Faced by Caregivers

Several studies have been conducted in recent years to understand the specific role and challenges faced by caregivers of renal patients undergoing dialysis and how caregiving impacts their well-being. Caregivers of patients with chronic kidney disease (CKD) have reported depression, fatigue, isolation, and burnout (Kalantar-Zadeh et al., 2021). They also experience physical and psychological disorders and have increased burden and impaired psychosocial well-being compared to controls (Adejumo et al., 2019). Living with an individual in the advanced stages of CKD and being the main caregiver is associated with challenges such as depression, anxiety, and burden (Kalantar-Zadeh et al., 2021).

Studies have also shown that family caregivers of patients receiving haemodialysis prefer the needs of patients over their own and ultimately spend less time on health-promoting behaviours that adversely affect their own health status and life routines. The burden of dialysis patient care does not only affect the caregiver but also the patient and leads to inadequate care of patients and patient

abandonment (Adejumo et al., 2019). Caregivers of children with kidney disease, for instance, reported feelings of stress, anxiety, depression, and insomnia during the COVID-19 pandemic, mirroring findings in parents of children with other chronic conditions (Sharma et al., 2022).

Overall, caregivers of renal patients undergoing dialysis have a significant burden of responsibilities that can impact their own well-being. Caregivers routinely take physical tasks such as assisting with dialysis, managing medications, and providing emotional support to the patient. They also manage their own health and well-being to avoid burnout and other negative outcomes. It is therefore important to provide support and resources to caregivers to help them manage their responsibilities and maintain their own health, too.

Social and Emotional Implications for Caregivers

A study on the quality of life among caregivers of people with end-stage kidney disease managed with dialysis or comprehensive conservative care found that informal caregivers of older people on dialysis had significantly worse care-related quality of life compared to those receiving comprehensive conservative care (Shah et al., 2020).

Another study assessing the level of burden among caregivers of patients undergoing haemodialysis, showed that a significant proportion of caregivers experienced mild to moderate burden including depression, fatigue, isolation, and burnout (Joseph et al., 2021). Other studies have, on the other hand emphasised the importance of recognising caregiver burden and

developing interventions to decrease it and increase patient support (Sharma et al., 2022).

These studies shed light on the social and emotional implications for caregivers of renal patients undergoing dialysis, highlighting the burden, challenges, and impact on their quality of life. They emphasise the need for support and interventions to address the specific needs of caregivers in this context.

Financial Burden and Socioeconomic Effects on Caregivers

A systematic review focusing on the relationship between financial hardship and symptom burden among patients receiving maintenance dialysis highlights the importance of strengthening financial assessments and support for patients receiving dialysis. It suggests that improved assessments of financial hardship are necessary to capture its extent and impact on patients throughout the disease trajectory (Ng et al., 2021).

Mental Health Challenges and Support for Caregivers

A mixed method systematic review study in 2022 found that caregivers of patients receiving conservative kidney management (CKM) experienced significant caregiver burden and similar impacts on their quality of life (QOL) (Walavalkar et al., 2022).

Epidemiology of haemodialysis outcomes article further suggests that developing educational and training programs tailored for families and caregivers can decrease the burden of knowledge and unexpected care needs. It also discusses the potential benefits of providing psychological support and coping skills to caregivers (Adejumo et al., 2019). Interventions such as education,

counselling, and support groups can, therefore, be instituted to significantly improve the well-being of caregivers of patients on dialysis (Chu et al., 2023).

METHODOLOGY

Research Design

The study adopted a qualitative research design to gain insights into caregivers' experiences. A qualitative research design is particularly suitable due to its ability to delve into the intricacies of human emotions, motivations, and behaviours (Sofaer, 1999). Accordingly, qualitative study design was preferred owing to its strength of enabling researchers to explain processes and patterns of human behaviour that can be difficult to quantify (Tenny et al., 2022). The research design involves conducting in-depth interviews with caregivers and using thematic analysis to identify patterns and themes within their narratives.

Study Population and Sampling

The population for this research consisted of dialysis patients' caregivers/partners in Kenya. According Maritim *et al.*, (2022), the prevalence of chronic kidney disease (CKD) stands at 4%. The characteristic prevalence is used in this study to calculate the sample size (number of caregivers targeted) used in this study. Caregivers/partners are individuals who provide support and assistance to dialysis patients, helping them with various aspects of their care, including medication management, transportation, dietary restrictions, and emotional support. The welfare as well as the quality of life of those on dialysis are significantly impacted by these caregivers/partners. This encompasses a diverse range of individuals, such as family members, spouses, friends, or hired

caregivers (Sherwood *et al.*, 2005). The population also constitute individuals from different age groups, genders, socioeconomic backgrounds, and cultural contexts. The sample size was calculated using Fisher *et al.*, 1998 formula for sample size determination.

$$n = \frac{z^2 P(1-P)}{E^2}$$

Where N is the sample size; Z is the Z-score corresponding to the desired confidence level; P is the estimated prevalence of the characteristic; E is the desired degree of accuracy.

$$N = \frac{1.96^2 0.04(1-0.04)}{0.05^2} = 59$$

59 Caregivers

Inclusion Criteria

- The study only included individuals who are currently providing care and support to dialysis patients, including family members, spouses, friends, or hired caregivers who are actively involved in the day-to-day care of the dialysis patients.
- Adult individuals (18 years or older) capable of providing informed consent to participate in the research study.

Data Collection Methods

In-Depth Interviews with Caregivers

The in-depth interviews were conducted as a part of a research study involving caregivers at the Kisumu Specialist Hospital in Kenya. Conducting this study at Kisumu Specialist Hospital was informed by the fact that the hospital has robust nephology services in Kisumu County. As such, it was easy to reach out to the caregivers of renal patients and draft them into the study.

The purpose of the interviews was to gain a comprehensive understanding of the experiences, challenges, and perspectives of caregivers in the context of their role in providing care to patients. Each in-depth interview session had a duration of approximately 90 minutes. This time frame allowed for a detailed exploration of the caregiver's experiences, ensuring that their perspectives were thoroughly captured. Caregivers who were eligible and willing to participate in the study were recruited from the hospital's caregiving community. To ensure ethical practices, the researchers followed a strict informed consent process. Caregivers were provided with comprehensive information about the study's purpose, procedures, potential benefits, and risks. They were provided the opportunity to ask questions and clarify any doubts before voluntarily providing their written informed consent to participate.

Participants' privacy and confidentiality were upheld throughout the research process, and pseudonyms or identifiers were used to maintain the anonymity of the caregivers in the interview transcripts and the subsequent publications. Data collected during the interviews were securely stored and accessed only to authorised research personnel.

Interview Guide Development

For developing an interview guide with open-ended questions that align with the research objectives the PubMed guideline was (<https://pubmed.ncbi.nlm.nih.gov/16649428/>) utilised for generating interview questions. The following steps were taken.

- Carefully read and analysed the research article to gain a clear understanding of its key

findings, research questions, and the context of caregiving to explore the main themes, concepts, and issues.

- Based on the understanding of the research article, the specific objectives were drawn.
- Identified the key themes or topics that emerged from the research article. These themes were used as the foundation for developing an interview guide.
- For each identified theme, open-ended questions were generated that encouraged participants to share their experiences, perspectives, and insights.
- A pilot test with a small group (10% —6) of the prospective study participants drawn from caregivers of kidney patients attending Kisumu Specialist Hospital. These caregivers were excluded from the actual study.
- Organised the open-ended questions in a logical sequence within the interview guide. Started with introductory questions to establish rapport and gradually moved into more in-depth and sensitive topics.
- Reviewed the interview guide to ensure that the questions aligned with the research objectives and effectively captured the desired information. Made a necessary refinement to enhance clarity, relevance, and coherence.
- Ensured that the interview questions were respectful and considerate of participants' feelings and potential vulnerabilities. Avoided any intrusive or offensive language and provided clear instructions about confidentiality and anonymity.

- Once the interview guide was refined and aligned with the research objectives, it was ready for use in data collection.

Recording And Transcription Procedures

Prior consent was obtained from each participant to record the interview sessions. The recordings served as an accurate reference for data analysis. After conducting the interviews, the recordings were transcribed verbatim. Transcription was carried out with utmost accuracy to preserve the richness of the caregivers' narratives.

The transcribed data was subjected to rigorous qualitative analysis. Themes, patterns, and insights emerging from the caregivers' accounts were identified and interpreted. The research findings were reported in a manner that protected the identities of the participants, using pseudonyms or codes to ensure anonymity.

Data Analysis

Qualitative Data Analysis Techniques

Qualitative data analysis involves various techniques and approaches to make sense of the rich and nuanced information gathered from participants' narratives.

Data Coding and Thematic Analysis

Data Coding

The recorded interviews were transcribed verbatim before the coding process was conducted. An inductive approach to coding was adopted, allowing themes and categories to emerge directly from the data. Two researchers independently coded a subset of the data to ensure inter-coder reliability. Coding discrepancies were resolved through discussion and consensus.

Thematic Analysis

Following the coding process, thematic analysis was conducted to identify overarching themes within the dataset. The researchers engaged in a systematic process of organising and analysing the coded data to identify patterns and connections. The themes were derived through a process of iterative coding and constant comparison, where codes were grouped together based on similarities and relationships.

Several key themes emerged from the data. These included:

- **Impact on Daily Routines and Responsibilities:** This theme focused on the changes and challenges faced by caregivers in their daily routines and responsibilities. Subthemes within this theme encompassed alterations in time management, adjustments to personal schedules, and the emotional and physical demands of caregiving.
- **Socioeconomic Effects:** This theme explored the financial implications experienced by caregivers. Subthemes included increased expenses related to medical care, transportation, and lifestyle adjustments. The theme also addressed income loss or work disruptions faced by caregivers and their overall financial well-being.
- **Mental Health Challenges and Coping Mechanisms:** This theme encompassed the emotional and psychological consequences of caregiving. Subthemes included stress, anxiety, and depression experienced by caregivers. Additionally, the theme explored the various coping mechanisms employed by caregivers to address their mental health

needs, such as seeking support from friends and family or engaging in self-care activities.

Content Analysis

Alongside the thematic analysis, content analysis was conducted to examine specific details within the data. This involved systematically analysing the text to identify keywords, phrases, or concepts that provided contextual information and enriched the understanding of the themes identified in the thematic analysis.

The combination of thematic and content analysis provided a comprehensive exploration of the data, enabling a deeper understanding of the experiences and challenges faced by caregivers of renal patients undergoing dialysis.

Ethical Considerations

Informed Consent Process

To ensure informed consent, the researcher provided a clear and concise explanation of the study's purpose, objectives, and procedures to the potential interviewees at Synergy Clinic, Kisumu Specialist Hospital. During the process, he emphasised voluntary nature of participation and that declining to participate would have no negative consequences them.

Written consent was provided after the briefing, and interviewees were given an opportunity to ask questions before they signed the written consent. To guarantee privacy and ensure confidentiality, the researcher used pseudonyms and codes in the transcripts and in reporting of the findings. All collected data, including consent forms, interview recordings, and transcripts, were securely stored on password-protected and encrypted forms only accessible by the researcher.

RESULTS

Saturation

The study targeted 59 caregivers of renal patient attending Kisumu Specialist Hospital. However, interview with caregivers were conducted until saturation (n=32), where further data collection was deemed unnecessary. Saunders *et al.*, (2017) observes that saturation has attained widespread acceptance as a methodological principle in qualitative research.

Socio-demographic Characteristics of the Respondents

Most of the study participants (62.5%) were 45 years and above, with a mean age of 48 years. In terms of gender, 75.0% of the participants were females, assuming a gendered connotation. Half (50.0%) of the study participants had O-level education, with the other half having advanced level education (college/university). In terms of occupation, most of the caregivers (37.5%) were in business, with the rest in agriculture (25.0%), teaching (25.0%) and social work (12.5%).

Table 1: Summary of Socio-demographic characteristics of the respondent

Demographic characteristic	Percentage (N=32)
Age	62.5% aged 45 years and above
Mean age	48 years
Gender	75.0% female, 25.0% Male
Education level	50.0% O-level, 50.0% Advanced level (University and college)
Occupation	37.5% Business, 25.0% Agriculture, 25.0% teaching and 12.5% social work
Relationship with the patient	62.5% Spouse, 37.5% Child

Impact of Caregiving on Caregivers Daily Routine

Reason for Assuming Caregiving Role

In order to build a coherent understanding of the impact of caregiving roles on the caregiver's daily routine, the participants were asked to provide reasons why they assumed caregiving roles. The study found that most of the respondents assumed caregiving roles since they were the only persons available at home to provide the care required by their patients. A participant mentioned that she assumed the role of caregiving since they have little children who cannot perform the same. In her exact words:

The patient is my husband, and we have two young children and so it is me who has to step in to be his caregiver (N8).

Another caregiver added that:

I was the only person available. Most of my brothers are out and engaged and I was the one most available around and we made arrangement with the brothers for me to receive support as I commit to support our father (N4).

This is further affirmed by another caregiver who stated:

I am the only person left. It was God's plan. All other siblings are deceased and am the one left alone with her has the only person she has close by.

However, other participants noted that they assumed the caregiving role because they were selected by family members. Nonetheless, they pointed out that they receive help from their

family members and sometimes take turns in caregiving. He explained that:

We have an arrangement in the family where I sometimes come or sometimes request the driver to bring him or when the children are around, they also step in to take their father to the clinic. The children are always willing and you have seen my daughters come with their dad to the clinic on a number of occasions (N21).

Experience Interacting with Renal Patients and Other Caregivers

The study aimed to establish caregivers' experiences while interacting with patients in the renal units. The participants were asked to comment on some of the things they have/have not liked about how the patients are attended to. In terms of caregiving experience and interaction with patients and other caregivers, a caregiver had this to say:

From my experience caregiving is quite intensive activity that requires time, commitment, and sacrifice. There should be a system that caters for caregivers since different caregivers have different needs (N1).

Other caregivers also revealed that the care their patients received was good and commended the doctors for doing their best. Participant N15 mentioned:

The care is good, the team is good and they do their best.

When asked about what they would like to be done differently, most of the participants refrained from making any proposal, while others expressed exhaustion and wished they could pass the

proverbial "baton" to someone else. This is what N6 had to say when asked about a proposal:

Cannot say anything. I am tired but no one to give this duty or pass this baton to.

Nonetheless, those who had something to propose asked that the general renal services provided be improved, for instance, the dietary provision during dialysis. Still, some made proposals along the lines of changing the time when the dialysis sessions are conducted. Examples of such proposals include:

....to have dialysis session at night or late in the evening by the clinic management. Because some patients are working and busy during the day (N12).

Disruption of Daily Routine by Caregiving Roles

The participants were asked how caregiving roles affected their daily routines such as occupation, education, or parenting, among others. Most of the participants revealed that the caregiving roles have disrupted their work schedules, leading to loss of income, reduced disposable income and foregone opportunities, among others. Some participants mentioned that they no longer do business as they used to do in the past. They have had to shift to other income-generation activities that enable them to be at home to attend to their caregiving roles. This is what Participant N21 revealed:

I no longer do business that I used to do in the past. I have shifted to poultry keeping which I can do easily from home.

Participant N12 also revealed that on Mondays and Thursdays, when she has to take her husband for dialysis, she has to open her business late in the

afternoon. For Participant N1, in the exact words, "There is the reality of mental health issues, forgone opportunities, lost income that are likely to occur as well as recognising the role as a caregiver is also key and must be performed regardless".

Other participants pointed out that their sleep duration has changed drastically as their patients require support with bathing and nutrition. On this, participants mentioned:

...routinely I wake up at 3 am to wash him, brush his teeth which he cannot do on his own and prepare what he will eat. You know he has not bathed on his own for the last 6 years (N20).

Balancing Caregiving roles with other Daily Errands

When asked about how they balance the caregiving roles with other daily errands, most of the study respondents submitted that they had found coping mechanisms that help them balance the two. Respondents in formal employment revealed that they have made arrangements with their employers who have supported them to perform their caregiving roles effectively. Participant stated:

I inform my boss the head-teacher where I serve as a teacher who allows me off when I need to support the patient... (N20).

Participant N1 also mentioned:

I have a very understanding employer. I have an arrangement with the employer to accommodate my inflexibility and it has worked well so far.

Moreover, some participants indicate that to balance the two, they have to delegate their duties to other people at the workplace as they attend to their caregiving roles or use money to get things done. A participant stated:

I now have to use money to handle things that I used to do myself in the past in the farm (N13)

Caregiver's Dietary Changes

The study sought to understand how the caregiver's diet has changed since assuming the caregiving role. Most of the participants revealed that they have had to shift to what their patients have been recommended to eat. Even so, they recognised that this has not been easy, but they must adapt, nonetheless. Participant N1 mentioned that taking the same diet with the patient is good for psychological support, hence the need to adjust appropriately.

Others however revealed that they have to cook for their patients separately. A participant mentioned.

He eats differently from us, and it is one of the expensive things for us.

Socioeconomic Effects Experienced by Caregivers of Renal Patients

Caregivers' Cost of Living

The study sought to establish how caregiving responsibility has impacted caregivers economically. All the study participants indicated that the cost of living has gone up since the assumption of caregiving roles. When asked why the cost of living has gone up, a majority of the respondents cited the dietary changes, medication, skyrocketing cost of dialysis and the increase in a

number of dialysis required or recommended per week. Some of the participants mentioned that the cost of living has not just gone up; it is very high, perhaps a revelation of how caregiving responsibility is overwhelming through a socioeconomic lens. A participant lamented:

Cost of life has gone high. Nowadays I have to hire a vehicle to bring her to the facility after she was hurt one day when the matatu crew pushed her out when she was alighting slowly in 2021 and she hurt in the process. She no longer walks on her own (N17)

Another participant observed.

Gone high. Our pockets have been eaten fully (N5).

Caregivers' Quality of Life

Almost tied to the question of the cost of living is the question of caregivers' quality of life after assuming caregiving roles. Most of the respondents observed that quality of life has deteriorated since the assumption of the caregiving role due to the financial burden it has placed on them and a lot of dietary adjustments they have had to make. Some of the participants lamented that the caregiving responsibility has led to a dramatic shift in their sleep patterns, hence impacting their general health outcomes. Participant N23 had this to say:

It has toughened for us. We use a lot of money on the patient. He is on and off hospital especially in the recent past due to problem with his fistula failing.

Some respondents also lamented that the caregiving role has left them destitute. Here is what participant N25 had to mention:

The quality of life has so much reduced. I cannot even do repairs in our living house because all the money goes to his treatment. Sometimes I do not even have a shilling and we have to come to the hospital and through God's grace we just get a way through. Brothers and relatives gave up on him long ago and there was even a time when he stayed in hospital, and they all knew he will not make it.

Caregivers' Expenditure on Patients' Health

The study sought to establish the aspects of health caregivers' spending on. Nearly all the respondents revealed that they spend the most money on buying the recommended drugs, blood boosters, and bone therapies. In terms of drug purchases, the respondents indicated that they are often required to buy drugs for hypertension and diabetes. Others also indicated that they must buy bacterial infection drugs.

Transplant As More Lasting Treatment?

When asked if they would consider organ transplant as a lasting treatment for renal patients, this question elicited mixed responses, with almost the same number indicating a YES and a NO. Those who indicated that they would consider a transplant cited that they would do it because of the relationship they have with the patient. Those who indicated that they would not consider organ transplants even if they are compatible mentioned that they do not want to also get complications that come with organ donation. Participant N14 mentioned:

Not sure if my age can allow it. I can also get some problems and I have also not tested my kidneys to know if I also have a problem.

Here is what participant N8 had to say:

Even if I wanted to donate, I would not because we have children who are still young, and they need parents and with transplant there is expensive medication. It can also make both of us sick and the children can suffer.

Experience with Mental health Issues

The study sought to establish the mental health challenges caregivers of renal patients undergoing dialysis grapple with. When asked whether their caregiving role has impacted their mental health status, all the respondents replied in the affirmative.

Mental Health Challenges for Caregivers

Table 2: Caregivers' mental health experience

Question	Frequency (N=32)	Percentage (%)
Has your role as a caregiver had any effect on your mental health state?	32	100

When asked how caregiving has had mental health effects on them, most of the respondents mentioned that they experience stress, especially when they are required to cater for the medical bills. Some participants lamented that having to be present with the patient, even in the renal unit, takes an emotional toll on them. For some, caregiving has evoked suicidal ideation. Participant 15 mentioned:

Sometimes you feel like you want to die.

The participant went on to say:

The stress is too much and you are always in deep pain and asking why

Other participants revealed that the caregiving role also makes them feel sick, especially when they think of where they will get money to take their patient to hospital.

You feel you are also sick always thinking where will money come from to pay medical bills or take him to hospital. Your brain is tired. (N23)

Caregivers Greatest Fears

The study participants were asked about their greatest fear while attending to their caregiving tasks. Most of the participants revealed that their greatest fear is a situation where the patient suddenly becomes ill and their health deteriorates, sometimes at the night when no one can help. The participants mentioned that health challenges are never-ending, but they have learned how to address those challenges. Participant N1 mentioned:

Emergencies that come up now and again. You are happy today and tomorrow you are low and in hospital and this is quite taxing in terms of emotions.

Participant N3 mentioned that her greatest fear the abrupt sickness that comes when they are just two people.

Caregivers Mental Health Coping Strategies

When asked about how they cope with the mental health challenges they experience as caregivers, most of the participants indicated that they have accepted their role and understand that it has its

fair share of challenges. As such, they have learned to live with the challenges while adopting other strategies such as sharing with other caregivers, survivors, and close family members. Others also acknowledged that prayers have been their source of strength when experiencing mental health breakdowns. Participant N20 mentioned:

Having my mum's company helps in share and relieving myself of such tensions and stress. When am away from the patient I get more worried.

When asked if they have contemplated giving up on their patients, a majority mentioned that they have never thought of giving up on their patients, while others confided that they have entertained the thought of giving up in the past. Here is what participant N28 had to say:

Never. My children cannot allow me to. Their father was this very strong man, and he was a soldier who was there for us.

Participant N21 mentioned:

I have contemplated giving up, but I had had to pick myself up again and continue with my caregiving responsibilities.

Motivation for the Caregiving Role

Relationships with the patient, knowledge of caregiving, and patient and doctor cooperation were identified as the main motivation to continue with the caregiving role. Nearly all the respondents were caring for patients who are close family members. As such, they mentioned that the love for the patient motivates them to the caregiving support. A participant stated:

Patient is cooperative and always wants to live. The doctor is also very good, and he has

allowed us to call him anytime we have a problem, and he will respond even in the middle of the night.

Participant N5 mentioned:

I am a CHV and am trained as a counsellor and this helps me in caring. It also requires a big heart and prayers too.

For Participant N17, her love for her mother is her source of motivation. She says:

I love her. If I get approached by men for marriage, I must reject the advances because I do not contemplate leaving my mother at any given time.

Support System Available for Caregivers?

When asked to indicate if there is any support from the medical facilities to address caregivers' concerns, most of the respondents observed that they receive no support. A participant mentioned:

Not support in particular but when there is a problem with patient while at home, I will call the Doctor and they take it normal helps you through and that releases the pressure one has.

What Could Be Done to Support Caregivers?

The study respondents were asked to recommend what could be done to support caregivers. Economic empowerment, training of caregivers on caregiving roles, cash-transfer programs, health insurance packages and transport facilitation feature prominently. Participant 19 recommended:

Government to give us something similar to the elderly cover to support caregivers; Can NHIF cover more medication like multi-

vitamins, blood boosters. Drugs are very expensive as well as transport to the facility. Patients sometimes ask the caregivers to leave them at home if they see the caregiver straining-saying everybody will die, and she can as well take a bow too.

Participant N24 said:

...to explore the possibility of getting alternative way to provide for the families of the caregivers. This can be through government supporting caregivers to start business or get some form of employment.

DISCUSSION OF RESULTS

Summary of the Findings

In summary, our study investigated the challenges faced by caregivers of renal patients undergoing dialysis in Kenya. Our findings indicate that the majority of participants were aged 45 and above (62.5%) and predominantly female (75%). Half of the caregivers had an O-level education, while the other half had advanced-level education. Business was the most common occupation (37.5%), followed by agriculture and teaching (both at 25%).

The study revealed that caregivers assumed their roles due to family circumstances, with some being the only available option while others were selected by family members. Caregivers faced disruptions in their daily routines, leading to economic repercussions such as loss of income and increased living costs. While they appreciated the medical care provided to patients, they suggested improvements to dietary provisions and dialysis session timings. Caregivers reported shifts in their sleep patterns and dietary changes.

The financial implications were significant, with most reporting increased living costs. Mental health challenges were prevalent, with stress and thoughts of self-harm being mentioned. Their greatest fear was the sudden deterioration of the patient's health, particularly at night. However, they coped through mutual support, faith, and acceptance.

Impact of Caregiving on Caregivers' Daily Routine

Reason for Assuming Caregiving Role

As revealed in our findings, many caregivers assumed their roles due to familial obligations. For instance, when the patient is a spouse, they often take on the role out of love and a sense of duty to their partner (N8). Such caregiving responsibilities, especially within familial structures, align with Pinquart & Sörensen, 2007 study which highlighted the significance of informal caregivers in supporting patients.

Furthermore, our research indicates that some caregivers, who were selected by other family members to provide care, often receive help and take turns in caregiving. This communal approach to caregiving has been observed in other studies, emphasising the collaborative nature of caregiving within families (Snyder *et al.*, 2015).

Experience Interacting with Renal Patients and Other Caregivers

Caregivers in our study generally expressed satisfaction with the care provided to their patients in renal units, acknowledging the dedication of healthcare professionals. This is in agreement with a study by Schulz & Beach, 1999 who observed that the quality of patient care has a direct impact on caregiver well-being and the overall perception and experience of healthcare services provided.

When asked about possible improvements to renal services, some caregivers suggested re-evaluating the timing of dialysis sessions, advocating for sessions in the evening or at night to accommodate patients who work during the day. This finding highlights the need for healthcare institutions to consider patient and caregiver feedback to optimise service delivery (Maclean et al., 2018).

Disruption of Daily Routine by Caregiving Roles

Findings illuminated how caregiving roles often disrupt caregivers' daily routines, impacting their livelihoods and sleep patterns. Caregivers spoke of reduced income and the need to shift to less time-consuming income-generating activities. Such economic challenges faced by caregivers are consistent with prior research emphasising the financial strain caregivers experience (Carmichael et al., 2010).

Additionally, the disruption of sleep patterns and daily schedules due to caregiving responsibilities was a recurrent theme. Caregivers reported waking up early to provide support, reflecting the physical and emotional toll caregiving can take (Cannuscio et al., 2002).

Balancing Caregiving Roles with Other Daily Errands

The ability of caregivers to balance caregiving responsibilities with other daily errands was often facilitated by understanding employers or the delegation of duties to others. Our research revealed that many caregivers have made arrangements with their employers for flexibility in their work schedules, ensuring they can attend to caregiving responsibilities. This highlights the importance of supportive workplace policies and caregiving arrangements that can help caregivers

manage their dual roles (Freedman & Spillman, 2014).

Some caregivers also mentioned using financial resources to delegate tasks they once handled themselves. This adaptive strategy allowed them to balance caregiving with other responsibilities. The ability to delegate or purchase services has been identified as a key coping mechanism in previous research (Kornides et al., 2017).

Caregiver's Dietary Changes

Most caregivers in our study reported adjusting their diets to align with their patients' dietary requirements. Such dietary shifts were often made for practical and psychological support reasons, demonstrating the caregivers' commitment to their role.

Conversely, some caregivers mentioned having to prepare separate meals for their patients, citing the increased cost as a challenge. Financial concerns related to dietary changes are consistent with the economic challenges caregivers face (Carmichael et al., 2010).

Socioeconomic Effects Experienced by Caregivers of Renal Patients

Caregivers' Cost of Living

Our findings underline the substantial economic impact of caregiving roles. Nearly all participants noted an increase in their cost of living since assuming their caregiving roles. This increase was attributed to several factors, including dietary changes, medication expenses, the rising cost of dialysis, and the recommended frequency of dialysis sessions. Many caregivers shared their experiences of financial strain, where additional expenditures and unexpected costs have disrupted their financial stability. The financial challenges

faced by caregivers in this study are consistent with those reported in previous research (Pinquart & Sörensen, 2011).

Caregivers' Quality of Life

The significant economic burden borne by caregivers in our study has had a profound effect on their quality of life. Caregivers reported a deterioration in their quality of life, attributing it to financial constraints and lifestyle adjustments necessitated by the caregiving responsibilities. These challenges have manifested as shifts in sleep patterns and general health outcomes, impacting the overall well-being of caregivers. Such findings align with earlier research, which has shown that caregivers experience a decreased quality of life due to the emotional and financial toll of their role (Cannuscio *et al.*, 2002).

Caregivers' Expenditure on Patients' Health

The primary health-related expenses for caregivers were the purchase of prescribed medications, blood boosters, and therapies for bone health. This significant financial responsibility placed on caregivers included costs associated with managing comorbid conditions such as hypertension and diabetes. The financial commitment to support the patient's health became an additional source of economic pressure on caregivers. This finding is consistent with the findings of a study by Powers *et al.*, 2005 which revealed that caregivers often incur substantial out-of-pocket expenses related to the patient's health.

Transplant as a More Lasting Treatment?

Our study inquired about caregivers' perspectives on organ transplant as a long-term treatment for renal patients. Responses were divided, with some

caregivers expressing willingness to consider transplantation while others had concerns. Those in favour highlighted their strong emotional bonds with the patients and their positive relationships with healthcare professionals. Conversely, those opposed to transplantation cited potential complications, financial burdens, and concerns about their own health. In the study by Thomas *et al.*, 2005, the uncertainty surrounding transplantation was reported as a common theme in caregiver literature, highlighting the complexity of the decision-making process in regard to organ donation.

Mental Health Challenges for Caregivers

Experience with Mental Health Issues

All participants in our study acknowledged that their roles as caregivers had an adverse impact on their mental health. The participants described various mental health challenges, including stress, emotional exhaustion, and even thoughts of self-harm. The finding of the present study is consistent with the findings of Pinquart & Sörensen, 2003 who reported that caregivers are among the most-at-risk population for developing mental health issues, such as depression and anxiety.

Caregivers' Greatest Fears

The primary concerns of caregivers revolved around their patients' abrupt deterioration in health, often in situations where no immediate assistance is available. These fears were heightened during nighttime emergencies when resources and support were limited. Such concerns are consistent with the caregiver literature, where apprehension regarding unforeseen crises and the inability to provide adequate care is a common theme (Visser-Meily *et al.*, 2005).

Caregivers' Mental Health Coping Strategies

While caregivers in our study acknowledged the emotional challenges they faced, they also shared strategies for coping. Acceptance of their role as caregivers, mutual support from family and friends, and spiritual practices like prayer were identified as essential coping mechanisms. These strategies served as protective factors that helped caregivers manage the emotional toll of their responsibilities (Cooper et al., 2008).

Motivation for the Caregiving Role

Participants identified several motivators for their caregiving roles. These included their close relationships with the patients, their knowledge of caregiving, and the cooperation between patients and healthcare professionals. The bond and love shared with the patient served as a powerful motivation for caregivers to continue their responsibilities. This intrinsic motivation is consistent with prior research, highlighting the importance of personal connections in caregiving roles (Sörensen et al., 2002).

Support System Available for Caregivers

While healthcare facilities do not provide specific support for caregivers, our research revealed that caregivers often receive assistance and guidance from healthcare professionals. The willingness of doctors to provide support and guidance was particularly noted by caregivers. Given *et al.*, 2008 agree with this assertion, noting that such support from healthcare professionals can significantly benefit caregivers in their challenging roles.

What Could Be Done to Support Caregivers?

To enhance support for caregivers, participants recommended various interventions. These included economic empowerment programs,

caregiver training, cash-transfer programs, expanded health insurance coverage, and facilitation of transportation. Schulz *et al.*, 2001 also highlighted several mechanisms for supporting caregiver while underscoring the importance of comprehensive support systems to alleviate the financial and emotional burdens on caregivers.

CONCLUSION

In conclusion, the study sheds light on the profound challenges experienced by caregivers of renal patients undergoing dialysis in Kenya. These caregivers, primarily spouses and children of patients, face significant disruptions in their daily routines, leading to economic and psychological burdens. The economic consequences include increased living costs, diminished quality of life, and substantial healthcare expenses, while the psychological impact encompasses stress, exhaustion, and, at times, thoughts of self-harm. The motivations for their caregiving roles are deeply rooted in love, relationships with patients, and the cooperation they receive from healthcare professionals. Despite the absence of dedicated support systems, caregivers find ways to cope, relying on acceptance, mutual support, and faith. This study highlights the critical need for comprehensive support mechanisms to mitigate the challenges faced by caregivers in their essential roles.

Key Recommendations

- **Enhanced Support Programs for Caregivers:** To alleviate the socioeconomic challenges faced by caregivers, it is crucial to establish and expand support programs. This should include economic empowerment initiatives, caregiver training, and cash-

transfer programs aimed at easing the financial burdens of caregiving. Such support systems would help caregivers manage their economic challenges effectively.

- **Comprehensive Health Insurance Coverage:** To mitigate the financial burden of caregiving, we recommend extending health insurance coverage to include a broader range of medications, such as multivitamins and blood boosters, commonly required by patients undergoing dialysis. This would significantly reduce the out-of-pocket expenses of caregivers and improve the affordability of caregiving.
- **Mental Health Support and Education:** Given the prevalent mental health challenges among caregivers, it is imperative to develop and implement mental health support and education programs specifically tailored to their needs. These programs should address stress, emotional exhaustion, and other psychological challenges caregivers face, ultimately improving their well-being and ability to provide quality care.

By implementing these recommendations, caregivers of renal patients undergoing dialysis can receive the support and resources they require to continue their vital roles effectively while maintaining their own well-being.

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