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Original Article

A scoping review of family caregivers' experiences in caring for patients with kidney failure undergoing haemodialysis: evidence from Sub-Saharan Africa.

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Abstract

Background

Kidney failure (KF) poses a significant burden and role changes on family caregivers who provide essential support to patients undergoing haemodialysis.

Objective

This scoping review synthesises available evidence on the caring experiences, challenges, and support needs of family caregivers of patients with kidney failure receiving haemodialysis treatment in Sub-Saharan Africa.

Charting Methods

Two reviewers independently selected articles based on the agreed search strategy and inclusion criteria. Following the selection process, both reviewers independently extracted data from the included studies to ensure accuracy and reliability of the findings.

Eligibility Criteria

The review included qualitative primary studies written in English that focused on family caregivers of patients with kidney failure receiving haemodialysis in Sub-Saharan Africa.

Sources of Evidence

Literature was searched across three relevant databases: PubMed, Medline, and ScienceDirect. The search strategy was designed to capture studies examining the experiences of family caregivers in the Sub-Saharan African context.

Results

The final review included two qualitative studies conducted in Rwanda and Tanzania between 2021 and 2025. Analysis of these studies revealed four major themes: healthcare provider-family caregiver interactions, challenges within the healthcare system and accessibility of dialysis treatment, the multidimensional impact of long-term caregiving, and coping mechanisms and adaptation strategies.

Conclusions

Family caregivers experience significant physical, emotional, social, and financial burdens while caring for kidney failure patients. Healthcare systems in Sub-Saharan Africa need to develop comprehensive support frameworks that address the needs of caregivers and improve patient outcomes.

Recommendations

Healthcare providers should prioritise the implementation of family-centred care training programs and establish structured communication protocols with caregivers.

Keywords: *family caregivers; haemodialysis; kidney failure; Sub-Saharan Africa; qualitative studies*
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Introduction

Kidney Failure (KF), previously referred to as End-Stage Renal Disease, represents a critical public health challenge globally, with particularly severe implications for low- and middle-income countries in sub-Saharan Africa. Globally, the estimated number of individuals with KF requiring renal replacement therapy (RRT) ranges up to 9 million, with the majority found in low- to middle-income countries (Fiseha et al, 2023). The worldwide rise in kidney failure is primarily due to the increased occurrence of diabetes, hypertension, obesity, and ageing (Ghonemy et al, 2016; Kumar et al, 2020).

KF is the terminal phase of chronic kidney disease (CKD), defined by a glomerular filtration rate (GFR) of less than 15 mL/min/1.73 m², which often necessitates renal replacement therapies, such as dialysis or kidney transplantation (Rout et al, 2025). To sustain life, patients diagnosed with kidney failure (KF) require maintenance through RRT. These therapeutic interventions are essential for managing the physiological consequences of renal insufficiency. Haemodialysis (HD) remains the most common type of kidney replacement therapy (KRT), accounting for approximately 69% of all KRT methods and 89% of all dialysis procedures worldwide (Bello et al, 2022).

The burden of KF extends beyond patients to encompass family members who serve as primary caregivers throughout the treatment journey. A recent study in Ghana revealed that the caregiving role affects the psychological, physical, social, and spiritual well-being of family caregivers of children with KF (Boateng et al, 2024). Feelings of hopelessness and despair have also been noted, along with the absence of a chance to get ready for the changes that arise from the illness impacting their child and their shifting roles (Ong et al, 2021).

The support provided by family caregivers to individuals with KF is strongly linked to better adherence to treatment, which in turn enhances their chances of survival and overall quality of life (Ibrahim et al., 2015). The role of caregivers in supporting individuals diagnosed with KF and undergoing HD is often overlooked, despite the significant challenges. A recent study highlighted that individuals diagnosed with KF and their family caregivers prefer interdisciplinary interventions that combine disease education with practical skills training to improve HD management capabilities (Sousa et al, 2023).

While HD offers life-sustaining treatment, it requires intensive family involvement and support, creating complex caregiving dynamics that remain understudied. KF treatment presents challenges across the African continent, where substantial populations of patients with KF confront significant barriers, including insufficient healthcare infrastructure and limited financial resources (Crosby et al, 2020). The absence of renal registries contributes to an absence of reliable statistical data concerning the prevalence of CKD and KF across the majority of African countries. This scoping review synthesises evidence to understand the experiences of family caregivers supporting KF patients undergoing HD in Sub-Saharan Africa.

Methods

In conducting this scoping review, it is essential to acknowledge that the protocol was not formally registered. A scoping review methodology was selected for its ability to map the breadth of research on experiences of family caregivers in caring for patients with kidney failure undergoing haemodialysis. The review was conducted according to the approach outlined by Arksey and O'Malley (2005), supplemented by the subsequent suggestions provided by Levac et al. (2010). The steps included specifying the research question, identifying relevant literature, selecting studies, mapping the data, and summarising and reporting the results. The results were reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews Extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al, 2018).

Review question

The review question that guided the scoping review was: "What are family caregivers' experiences in caring for patients with kidney failure undergoing haemodialysis in Sub-Saharan Africa? ".

Eligibility criteria

Inclusion of studies for this review was contingent upon specific criteria aimed at capturing the nuanced experiences of family caregivers of patients with KF undergoing HD. Eligible studies included qualitative designs, such as phenomenological, descriptive qualitative, grounded theory, ethnographic, or mixed-methods studies with qualitative components, published in peer-reviewed journals between 2016 and 2025. The focus was on research conducted within Sub-Saharan Africa, exploring caregivers' challenges, support needs, and overall burdens in both community and hospital settings.

Conversely, studies were excluded if they employed purely quantitative methodologies, centred solely on patient perspectives, or focused on treatment modalities such as peritoneal dialysis and kidney transplantation, which do not involve haemodialysis. Studies lacking methodological rigour or presenting incomplete data were also omitted to ensure the integrity and relevance of the review.

Search strategy

The search was conducted from January to July 2025. The search strategy included searches from PubMed, Medline, and ScienceDirect, as these three databases collectively cover a broad scope of health studies. using key terms: "family caregiver, "End-stage renal disease," "ESRD,"

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"haemodialysis," "chronic kidney disease," "Kidney Failure," and "Sub-Saharan Africa." Boolean operators (AND, OR) were used to combine search terms. Names of the countries located in the SSA were used to ensure a broader search. Manual reference screening and citation tracking supplemented database searches.

Selection of sources of evidence.

All citations deemed relevant after title and abstract screening were procured for subsequent review of the full-text article. The authors developed a form to confirm relevance and extract study characteristics, including author details, publication year, design, population, sample, and the study's objective. Any discrepancies between the two reviewers were resolved through discussion and consensus. Where clarification was needed regarding study details or findings, the reviewers referred to the source material to confirm accuracy. Studies meeting all inclusion criteria after full-text review were kept for data extraction. The reference lists of included studies were hand-searched for any articles that may have been missed in the initial searches.

Data analysis, collating, summarising, and reporting results

The findings from the selected studies were organised and summarised to provide a comprehensive overview of family caregivers' experience in caring for patients with kidney failure undergoing HD. The authors employed a narrative synthesis approach, which enabled the integration of findings from diverse methodological backgrounds and drew broader conclusions about the overall trends and key issues identified in the literature.

Results

The search strategy yielded 63 results. This was reduced to 51 after duplicates were removed. Following title and abstract screening, 40 articles were excluded as they did not meet the inclusion criteria. Reasons for exclusion at this stage included articles that reported on different topics. After the full-text review stage, two articles were deemed eligible and included in the final review. A PRISMA-ScR flowchart has been provided to summarise the study identification process, as shown in Figure 1.

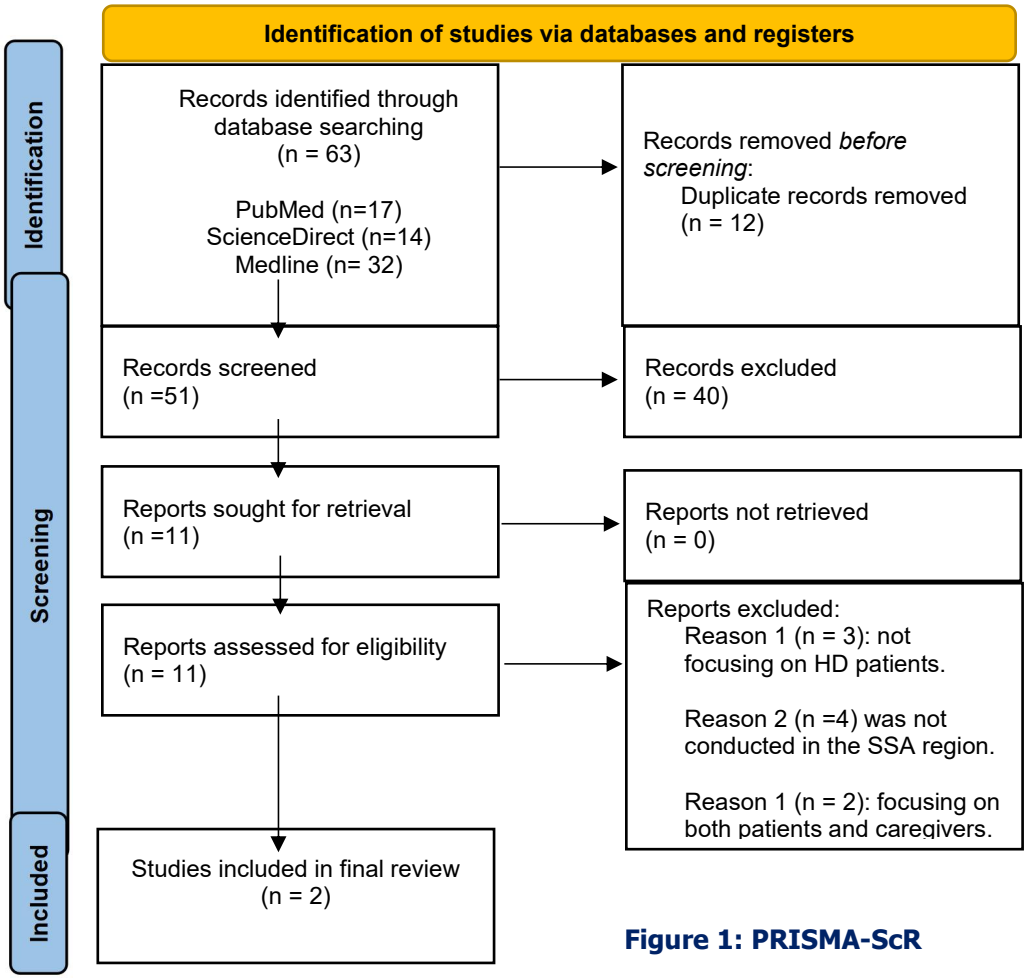

Figure 1: PRISMA-ScR

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A limited number of studies were identified in this area, highlighting the scarcity of research on family caregivers in healthcare settings. Two notable studies were found: one conducted in Rwanda and another in Tanzania. This lack of extensive research underscores the need for more comprehensive investigations to better understand the experiences and challenges faced by family caregivers. Table 1 presents the characteristics of the two studies included in this review.

Table 1: Summary of studies in the final review

Author and year of publication	Objective of the study	Country	Methods and design	Population and sample
Nkuranyabahizi et al, 2021	To explore the experiences of caring and support needs of the family caregivers of patients with ESRD at selected haemodialysis units in Rwanda	Rwanda	Descriptive Qualitative design	12 purposefully sampled participants. The population included family caregivers of either adults or paediatric patients with ESRD on haemodialysis in a selected renal unit.
Magenge et al 2025	To explore the experiences of FCGs of patients undergoing hemodialysis treatment at Muhimbili National Hospital	Tanzania	Qualitative-phenomenological design	14 purposefully sampled family caregivers of patients receiving hemodialysis services

Thematic synthesis

Theme 1: Healthcare Provider-Family Caregiver Interactions

The relationship between healthcare providers and family caregivers emerged as a critical factor influencing caregiving experiences across both studies. Communication barriers represented a fundamental challenge, with caregivers consistently reporting inadequate engagement with healthcare professionals. Magenge et al. (2025) revealed how provider attitudes varied significantly, with interactions dependent upon individual healthcare worker characteristics, workload pressures, and the approach taken by caregivers themselves. This inconsistency created uncertainty and frustration among caregivers who struggled to predict the quality of communication they might receive during clinical encounters.

Information sharing deficits further compounded these relational challenges. Nkuranyabahizi et al. (2021) found that family caregivers expressed strong desires for comprehensive information about treatment procedures, care plans, and management of disease-related complications. Similarly, Magenge et al. (2025) identified caregiver requests for dedicated time allocations to facilitate meaningful dialogue with healthcare teams. The absence of structured communication protocols left caregivers feeling excluded from critical care decisions, positioning them as passive recipients of medical directives rather than active partners in treatment planning.

Despite these challenges, some caregivers in both studies acknowledged instances of supportive provider interactions. Nkuranyabahizi et al. (2021) documented appreciation for healthcare professionals who demonstrated empathy and provided accessible contact information for emergency consultations. These positive encounters highlighted the potential for constructive provider-caregiver relationships when adequate attention and respect were afforded to family members' concerns and contributions.

Theme 2: Healthcare System Challenges and Treatment Accessibility

Structural limitations within healthcare systems significantly impacted caregiver experiences and treatment accessibility across both contexts. Financial barriers emerged as perhaps the most pervasive challenge, though manifestations differed between countries. Nkuranyabahizi et al. (2021) identified specific problems with Rwanda's Community-Based Health Insurance (CBHI) system,

which provided coverage limited to six weeks of HD treatment, creating significant financial stress for families requiring long-term dialysis support. This policy limitation forced families to seek additional resources or face treatment interruptions that threatened patient survival.

In Tanzania, Magenge et al. (2025) documented how high out-of-pocket costs disproportionately affected uninsured families, compelling them to reduce treatment frequency or postpone sessions entirely. The economic burden was particularly severe for families dependent on daily income-generating activities, as caregiving responsibilities conflicted with work obligations, creating a vicious cycle of reduced earning capacity concurrent with increased medical expenses.

Infrastructure limitations compounded financial challenges across both settings. Magenge et al. (2025) described how equipment shortages, including insufficient dialysis machines relative to patient demand, created extended waiting periods that delayed critical treatment and exacerbated patient deterioration. Staff shortages further contributed to service delays, with both studies documenting how understaffing affected treatment scheduling and the quality of care provision. These systemic inadequacies placed additional stress on family caregivers who witnessed their loved ones' suffering while feeling powerless to secure timely, adequate treatment.

Theme 3: Multidimensional Impact of Long-Term Caregiving

The burden of caring for KF patients manifested across multiple dimensions of caregiver well-being, with both studies revealing profound impacts on physical, emotional, economic, and social aspects of family life. Physical consequences were universal among participants, with chronic fatigue and sleep deprivation representing the most reported symptoms. Magenge et al. (2025) revealed that caregivers consistently experienced less than four hours of sleep per night due to patient care demands, resulting in persistent exhaustion that compromised their own health and functional capacity.

Emotional and psychological impacts were equally significant, with both studies identifying heightened stress, anxiety, and feelings of helplessness among family caregivers. Nkuranyabahizi et al. (2021) found that prolonged caregiving exposure led to mental health deterioration, with some participants reporting symptoms suggestive of psychological distress requiring professional intervention. The chronic nature of KF created sustained emotional demands that exceeded many caregivers' adaptive capacities, particularly when combined with financial stress and inadequate healthcare system support.

Economic consequences extended beyond direct medical costs to encompass broader disruptions to livelihoods. Both studies documented how caregiving responsibilities forced many participants to abandon income-generating activities, resulting in business closures, employment termination, and depletion of household savings. Magenge et al. (2025) particularly emphasised how the financial burden created cascading effects on family stability, affecting children's education, housing security, and the provision of basic needs.

Social impacts manifested through relationship strain, isolation, and geographic displacement. Nkuranyabahizi et al. (2021) documented how extended family members often withdrew support over time, leaving primary caregivers feeling abandoned during critical periods. Geographic displacement represented another significant social consequence, as families relocated to urban centres to access dialysis services, severing community connections and support networks that had previously provided resilience.

Theme 4: Coping Mechanisms and Adaptation Strategies

Despite overwhelming challenges, family caregivers demonstrated remarkable resilience through various adaptive strategies. Religious and spiritual coping mechanisms emerged as the predominant coping strategies across both cultural contexts. Nkuranyabahizi et al. (2021) found that caregivers drew strength from prayer, scriptural references, and belief in divine purpose, with many viewing their caregiving role as spiritually meaningful despite its difficulties. However, this spiritual reliance sometimes created additional conflict when caregiving demands prevented attendance at religious services, creating tension between spiritual needs and practical obligations.

Personal satisfaction derived from fulfilling cultural expectations of family care provided another significant coping resource. Both studies documented how caregivers found meaning in honouring traditional values of family responsibility and interdependence. Nkuranyabahizi et al. (2021) particularly emphasised how participants drew motivation from intergenerational transmission of caring values, viewing their role as a continuation of the cultural heritage passed down by parents and grandparents.

Peer support and experience sharing represented valuable but underutilised coping resources. Magenge et al. (2025) identified how informal interactions with other caregivers provided emotional support and facilitated the exchange of practical knowledge. These connections provided validation of experiences and strategies for managing common challenges, although both studies suggested that more structured peer support opportunities could further enhance caregiver resilience and adaptive capacity.

The studies conducted in Rwanda and Tanzania reveal significant similarities in the experiences of family caregivers within the SSA despite variations in healthcare systems and policy frameworks. Nkuranyabahizi et al. (2021) and Magenge et al. (2025) demonstrate that the burden of caregiving in KF transcends national boundaries and is exacerbated by systemic challenges inherent in the

region's healthcare infrastructure and cultural caregiving norms. The predominance of female caregivers aligns with established gender role patterns in sub-Saharan Africa, where women often assume the primary responsibility for family health. This gendered caregiving responsibility generates vulnerabilities, particularly in the face of economic instability and inadequate healthcare support. Both studies indicate that caregiving obligations frequently compel women to relinquish income-generating activities, thereby intensifying household financial strain during periods of elevated medical expenses.

Furthermore, the studies identify critical communication deficits between healthcare providers and family caregivers as pivotal intervention points. Inconsistent provider attitudes and gaps in information sharing, as documented by Magenge et al. (2025) and Nkuranyabahizi et al. (2021), reveal a failure within healthcare systems to recognise family caregivers as integral partners in chronic disease management. This oversight represents a substantial missed opportunity, as engaged family members could enhance treatment adherence, improve patient outcomes, and alleviate provider workloads.

Financial barriers emerge as the most significant structural challenge, manifesting differently across the two contexts. Rwanda's limitations in Community-Based Health Insurance (CBHI) and Tanzania's reliance on out-of-pocket payments impose unsustainable financial burdens on families. These findings align with broader literature on chronic disease management in low-resource settings, emphasising the urgent need for policy reforms that address the ongoing demands of KF care.

Despite these challenges, the resilience demonstrated through religious coping mechanisms and cultural meaning-making within SSA communities suggests potential strengths that could be harnessed to bolster caregiver support. However, both Nkuranyabahizi et al. (2021) and Magenge et al. (2025) illuminate how these cultural resources may simultaneously become sources of additional stress, particularly when caregiving demands intersect with spiritual practices or social obligations.

Conclusions

This scoping review represents the first comprehensive synthesis examining the experiences of family caregivers caring for individuals diagnosed with KF undergoing haemodialysis in Sub-Saharan Africa. Despite limited studies highlighting critical research gaps, findings from Rwanda and Tanzania reveal the multidimensional nature of caregiver burdens. Family caregivers face multifaceted challenges across physical, emotional, economic, and social domains, with inadequate communication from healthcare providers, financial barriers, and infrastructure limitations creating profound adversity. As non-communicable disease burden rises across sub-Saharan Africa, these findings demand immediate action to expand research, implement healthcare reforms, and systematically integrate family caregivers into sustainable care delivery models.

Strengths and Limitations

The major strength of this review is that, to our knowledge, it is the first to analyse the existing literature on family caregivers' experiences caring for patients with KF undergoing HD in the Sub-Saharan region. This scoping review has several limitations. First, its geographic focus is limited to two countries within the Sub-Saharan African region, which may restrict the generalisability of the findings. The sample size is also small, comprising only 26 caregivers, which may overlook diverse experiences. Lastly, the studies were conducted over different time periods, reflecting the evolving healthcare contexts that may have influenced the insights gathered.

Recommendations

To enhance healthcare delivery for both caregivers and patients, several key recommendations can be made across different sectors. Healthcare providers should prioritise the implementation of family-centred care training programs and establish structured communication protocols with caregivers. Additionally, developing caregiver assessment and support protocols may improve their overall experience and effectiveness. In terms of healthcare systems, it is essential to invest in the expansion of dialysis infrastructure. Equally important is the development of support services tailored explicitly for caregivers and addressing staff shortages through focused training and retention initiatives.

Formulating national strategies to support caregivers. Future research should aim to conduct multi-country comparative studies and develop innovative caregiver intervention programs. Furthermore, exploring methodologies for economic impact assessments and investigating cultural adaptation strategies for support programs will be vital in creating effective resources and solutions.

List of abbreviations

HD Haemodialysis
KF Kidney Failure
SSA Sub-Saharan Africa
ESRD End Stage Renal Diseases
CBHI Community-Based Health Insurance
RRT Renal Replacement Therapy

Conflict of interest.

The authors declare that they have no competing interests.

Availability of data

All the data generated or analysed during this scoping review have been included in this manuscript.

Author's contribution.

SB conceptualised the review. SB and SAN developed the search criteria and conducted a comprehensive search for, consolidation of, and analysis of the data. Both authors fully endorse the final version of the submitted manuscript.

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Competing interests

The authors declare that they have no competing interests.

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