

ORIGINAL RESEARCH

Burdens and challenges of hospital-based informal caregiving in Africa: A scoping review

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ABSTRACT

Introduction: Informal caregivers (ICs) play a crucial role in healthcare, particularly in resource-limited settings where they help alleviate staff shortages. Despite their invaluable contributions, the literature on the challenges of ICs remains sparse. This scoping review addresses this gap by exploring the burdens and challenges faced by those engaged in hospital-based informal caregiving in African contexts. The study focuses on ICs in African hospital environments, acknowledging the unique challenges posed by structured hospital settings.

Methods: This scoping review systematically searches relevant literature from 2000 to 2024, concentrating on African hospital settings. Databases including Web of Science, Medline, PsycINFO, SociIndex, CINAHL, Africa-wide, Academic Search Complete, and PubMed were queried. Abstracts were independently assessed for relevance, and potentially eligible studies' full texts were examined by two authors. Papers were selected based on the following inclusion criteria: (1) they reported on the burdens and stress experienced by informal caregivers; (2) they focused on research conducted in Africa; (3) they were published in English; and (4) they were published between January 1, 2000, and August 31, 2024.

Results: The review included 26 eligible studies, with a majority conducted in Nigeria (n=6), followed by four each in South Africa and Uganda. Thirteen studies employed qualitative methods, ten utilized quantitative methods, and three adopted mixed methods. Qualitative approaches were primarily interview-based, with limited use of ethnographic methods or group-based techniques like focus group discussions. Family members, including spouses, parents, siblings, and extended relatives, commonly assumed caregiving roles. The themes include the physical health burden of caregiving, socio-economic challenges, emotional distress and social isolation, and family strain.

Conclusion: This scoping review provides valuable insights into an overlooked aspect of African healthcare, shedding light on the challenges faced by ICs. By addressing this knowledge gap, it lays the groundwork for future research, policy development, and interventions to support informal caregivers in African hospital settings.

Keywords: Africa; hospital-based; informal, caregiving; hospitalisation; caregivers; burden.

Abstract in Español at the end of the article

INTRODUCTION

Informal caregivers (ICs) play a key role in the healthcare landscape, especially in under-resourced settings where they help address staff shortages [1]. These caregivers are dedicated to providing essential support to patients. While various studies have explored informal caregiving globally [2-5], the challenges faced by ICs remain underrepresented in the healthcare literature, particularly in African hospital settings [1]. This scoping review aims to investigate the unique burdens and challenges of hospital-based informal caregiving in Africa, contributing to a deeper understanding of this critical issue.

The World Health Organization (WHO) defines caregivers as individuals without formal health training who are not employed by the hospital but are present as “carers” or “guardians” for known patients in hospital settings [6]. In this study, ICs refer to unpaid individuals—typically family members, friends, or significant others—who assist hospitalized patients in Africa [7]. They take on various responsibilities, including medication administration, appointment scheduling, grocery shopping, mobility assistance, and emotional support [8]. Despite their crucial role in patient care, ICs encounter numerous challenges and burdens. Caregiver burden is defined as a psychological condition stemming from the combination of physical tasks, emotional strain, and social pressures associated with caring for an ill patient [9].

Some studies have highlighted the burdens faced by informal care givers. Blair and colleagues [6] revealed that ICs in the United States struggle with tasks like buying appropriate food, administering medication, and assisting with mobility. In Nigeria, a study [10] reported a caregiving burden prevalence of 96% among ICs of acute stroke patients, while another study [11] found that both male and female caregivers experienced high burden levels, making them vulnerable to depression. Chukwu and colleagues [12] identified additional challenges, including constant care responsibilities, an uncomfortable hospital environment, and reluctance from formal caregivers to assist patients without ICs. Financial strains also contribute to significant stress and exhaustion among caregivers, highlighting the need to prioritize their well-being in healthcare support.

In recognition of the important role and challenging experiences of informal caregivers, several high-income countries have adopted diverse policy approaches to address caregiver needs. Specifically, countries such as the United Kingdom, Australia, and New Zealand, have implemented national caregiver strategies that serve as policy “umbrellas” to coordinate and develop various measures. For example, the UK has had a National Strategy for Carers since 1999, supported by several Acts of Parliament, providing direct services and assistance to caregivers, along with social security benefits. Australia’s National Carer Strategy, aligned with the Carer Recognition Act (2010), works alongside the National Disability Strategy to respect and support caregivers, en-

surging their rights and opportunities in economic and social life. These strategies reflect international precedents for comprehensive informal caregiver support policies [13].

However, strategies and policy frameworks to address the burdens and needs of ICs are lacking in many parts of Africa, with little attention paid to the situation of relatives supporting hospitalisation care in health facilities. In fact, notable gaps persist in the existing literature concerning the situation of ICs providing hospital-based informal caregiving across Africa. By “hospital-based informal caregiving”, we mean informal care provided by family/relatives/friends to support a patient who is admitted and receiving care at any healthcare facility.

Africa serves as an important setting for exploring how ICs experience hospital-based care because of its diverse cultural, economic, and healthcare contexts. For one, hospitals are an integral component of the healthcare system, which is often characterized as “total institutions” with stringent rules governing both patient care and staff conduct. In this structured environment, the role of ICs is expanding and becoming a vital element in hospitalisation care [14]. The involvement of ICs in hospital-based care likely imposes substantial burdens on family members in ways that home-based care may not. That is, hospitals represent unique and critical contexts for informal caregiving where caregivers may be required to navigate complex medical procedures, manoeuvre health systems, manage the emotional and psychological well-being of their loved ones, coordinate with healthcare professionals, and cope with the stress and uncertainty that often accompanies hospitalization. These unique challenges demand specific attention within the caregiving literature, as they have direct implications for both the ICs’ well-being and the quality of patient care.

In addition, there is a notable gap in existing literature regarding context-specific dynamics that shape experiences of hospital-based informal caregiving. While caregiving has been extensively studied in various contexts globally, there is a paucity of research that explores the situation of ICs in African hospital environments. This gap is not merely an oversight but represents a significant knowledge deficit that can hinder the development of targeted interventions, policies, and support systems for caregivers in Africa. Moreover, the emphasis on the African context is particularly relevant due to the significant disparities in healthcare systems, socioeconomic conditions, and cultural factors that exist across different regions of the world. This review focuses on the African context as it recognizes the need to address the specific concerns of caregivers in this region and acknowledges that a one-size-fits-all approach to informal caregiving research is insufficient.

Furthermore, identifying methodological gaps within the hospital-based caregiving literature is crucial for the advancement of research in this field [15], because

a rigorous and well-structured methodology is essential for producing reliable and valid findings [16]. By highlighting methodological shortcomings, researchers can enhance the overall quality of studies on hospital-based caregiving, both in Africa and worldwide.

This scoping review examines the burdens and challenges faced by informal caregivers of hospitalized patients in African contexts. The review also seeks to identify key gaps in the literature and methodological issues in current research. We aim to identify under-researched areas and suggest improvements for future studies, which could lead to more effective policies and robust findings.

METHODS

This review adopts the framework developed by Arksey and O'Malley (2005) [17] to conduct a comprehensive scoping review, with a specific focus on shedding light on the burdens and challenges of ICs providing hospital-based informal caregiving in Africa.

Identifying relevant studies

An exhaustive search in Web of Science, Medline, SociIndex, Health Source, CINAHL, Africa-wide, Academic Search Complete, and PubMed was conducted, for the period between January 2000 and 30 August 2024. We also searched the reference list of all eligible papers. This scoping review also included dissertations from the reference list and conference abstracts. The search strategy was informed by the Population, Concept, and Context (PCC) framework and was completed using a combination of terms in three areas: population (e.g., "family or informal care givers in Africa"), context (hospitals in Africa) and concept (e.g. primary research to explore the burdens, stress, and perspectives of informal caregivers) [18].

Our search period spans from 2000 to 2024, providing a comprehensive view of the research on informal caregiving in hospitalized settings in Africa. This timeframe is relevant due to significant advancements in healthcare, evolving caregiving practices, and shifts in healthcare policies globally, including in African nations. Additionally, the 21st century has brought increased awareness of the challenges faced by ICs and a growing body of research, facilitated by the expansion of online databases and electronic journals. This makes the period appropriate for a scoping review of the burden and challenges faced by ICs in Africa. Based on the aims of the review, the keywords used have been detailed in Supplementary Table 1S. The search strategy considered the specific search fields, command function, and vocabulary of each of the databases used. The search strategy was limited to publications in English.

Study selection

Papers were selected based on the following inclusion criteria: Studies must be conducted in an African hospital setting; Participants must be ICs of hospitalized

patients in Africa; Studies must report on the burden and/or challenges of ICs; Studies must be published in English and between January 2000 to August 2024. To be as inclusive as possible, we did not limit studies by type of disease, study design or methods. We imported all references from the online databases into Endnote, which was used to collate retrieved records. We also used Endnote to identify and remove duplicates. Two reviewers (KOA and ODS) independently screened all articles based on their titles, abstracts, and full-text articles to determine their eligibility for inclusion. Any disagreements were resolved through discussion between the two reviewers or with a third reviewer (MOO) if necessary.

A rigorous and systematic approach was employed to ensure methodological transparency and robustness. To manage the screening process efficiently, the authors meticulously documented the reasons for excluding papers that did not meet the eligibility criteria. These exclusion reasons were methodically recorded in an Excel spreadsheet, allowing for a transparent overview of the selection process.

Data extraction

Data extraction was carried out using the established guidelines and methodology provided by the Joanna Briggs Institute (JBI). The JBI approach is designed to present an exhaustive and impartial synthesis of a substantial number of pertinent studies within the confines of a single journal article [19]. This is accomplished through the application of rigorous and transparent research methodologies. This systematic data extraction process ensured consistency and reliability in gathering relevant information from the selected studies. The extracted data were subsequently organized, summarized, and analysed using a thematic analysis approach. Data extracted included study context, definition of a caregiver, sample size, characteristics of caregivers, health measure, and type of methods used for data collection in the study.

We employed thematic analysis to identify and explore key themes and patterns related to the burdens and challenges faced by informal caregivers in African hospital settings [20, 21]. To initiate the thematic analysis, we thoroughly reviewed the data, paying close attention to the phrases that encapsulated various dimensions of caregiver burdens. This process involved several key steps: first, we immersed ourselves in the data, allowing for a deep understanding of the nuanced experiences shared by caregivers. We systematically coded the responses, highlighting recurring themes and patterns that emerged from the data. Particular attention was paid to the emotional, physical, and social challenges that caregivers face, as well as the coping strategies they employ. Through this iterative process, we were able to extract complex information into coherent themes that reflected the diverse realities of caregiver experiences. This approach ensured a comprehensive exploration of

the caregiving burden and challenges, capturing the diverse ways in which caregivers might encounter difficulties while providing care to hospitalized individuals.

As the analysis progressed, data points were organized and clustered based on commonalities and recurring motifs. This iterative process involved constant comparison and refinement of emerging themes to ensure accuracy and reliability. Two of the researchers (KOA and ODS) engaged in discussions to resolve any discrepancies and to enhance the depth of interpretation. The final set of themes was determined through a consensus-driven approach, where the researchers collectively agreed upon the most salient and representative themes that encapsulated the various dimensions of caregiver burdens and challenges. This methodological rigor and transparency in thematic analysis contributes to the robustness of the findings. The emergent themes derived from the data are presented and discussed in the results section. Two authors independently assessed the quality of the included studies and discrepancies were resolved through discussion or with a third reviewer if necessary.

Patient and public involvement

There were no patients involved.

RESULTS

Eligible studies included in the review

Figure 1 presents the PRISMA flow diagram describing the process of study selection and reasons for study exclusion. A total of 2438 titles and abstracts were screened. After removing duplicates, 91 articles were subjected to a full-text review, and a final 26 studies were considered eligible for inclusion in the review.

Characteristics of included studies

Below we present a summary of key characteristics of the 26 eligible studies included in our scoping review. More than half of the papers were published between 2018–2024 as shown in Figure 2.

Most the studies were conducted in Nigeria (n=6), followed by four studies in South Africa, and Uganda. Among the studies selected, thirteen used qualitative methods, ten employed quantitative methods, and three used a mixed methods approach. The qualitative approaches adopted in the studies were limited to interviews. One of the qualitative studies employed data collection techniques such as FGD and photovoice [22]. However, the study did not report specific findings related to their photovoice research in published article.

Nine of the studies did not specify the diseases of the patients. Six of the studies focused on the burden associated with providing care to cancer patients [23–27] and two focused on stroke patients [10, 28]. One of the studies focused on caregiver burden associated with different diagnoses which ranged from HIV/AIDS, hypertension, diabetes mellitus, congestive heart failure, anaemia, and stroke [29]. The remaining studies focused

on cerebral palsy, surgical site infection, traumatic injury, end-stage renal diseases, and end-of-life care.

Only a few of the studies explicitly defined the concept of caregiving or highlighted the meaning of an informal caregiver. Nonetheless, there is significant convergence across the definitions provided. For instance, Akosile and colleagues [10] defined the IC as the primary caregiver—the person, whether or not related to the patient, who spends the most time providing daily care or who takes on the main caregiving tasks. Folashade and colleagues [30] described an IC as a family caregiver, which includes relatives or friends who provide care for a sick family member either in the hospital or at home. A study in Rwanda conceptualized the caregiver as an unpaid individual who cared for a patient with end stage renal disease for at least 6 weeks [31].

Similarly, the majority (90%) of the studies highlighted the relationship between the patient and the caregiver. Many of the caregivers were spouses, parents, siblings and extended family members such as grandparents. The socio-economic characteristics, including the educational background and work status of the caregivers, exhibited similarities across the studies. A clear gender difference in caregiving emerged, with over 60% of caregivers being female in half of the reviewed studies. Caregiver ages ranged from 18 to 69 years (See Table 2S in the Supplementary material).

Eleven studies mentioned the living arrangements of caregivers and the travel time required to reach hospitals. For example, a study in Kenya found that most caregivers lived outside Nairobi County and had to travel up to 600 kilometers across the country to access treatment, which is primarily available in the capital city [32]. Another study in Uganda highlighted transportation costs to the hospital, which ranged from 2,000 to 6,000 UG Shillings (approximately \$0.69 to \$2.06) per day, depending on the mode of transport (taxi or boda). However, it was unclear who covered these costs—whether informal caregivers paid out of pocket or relied on care recipients to cover transportation expenses [29].

The studies collectively explore the physical, financial, and socioeconomic challenges faced by family caregivers in various contexts. One focus is on caregivers of children with cancer, with investigations in Ghana and South Africa highlighting the emotional, social, and financial burdens they experience [23, 33]. Similarly, the socioeconomic experiences of parents with children undergoing leukemia treatment in Kenya [32] and the financial strains on informal caregivers in Nigeria and during pediatric oncology care underscore the significant challenges these families encounter [24].

In addition to socioeconomic factors, the emotional and psychological aspects of caregiving were documented. One study assessed the burdens on families caring for pediatric oncology patients in Egypt and the psychological experiences of caregivers during their children's cancer treatment. One study in Uganda also revealed the emotional and economic challenges faced by

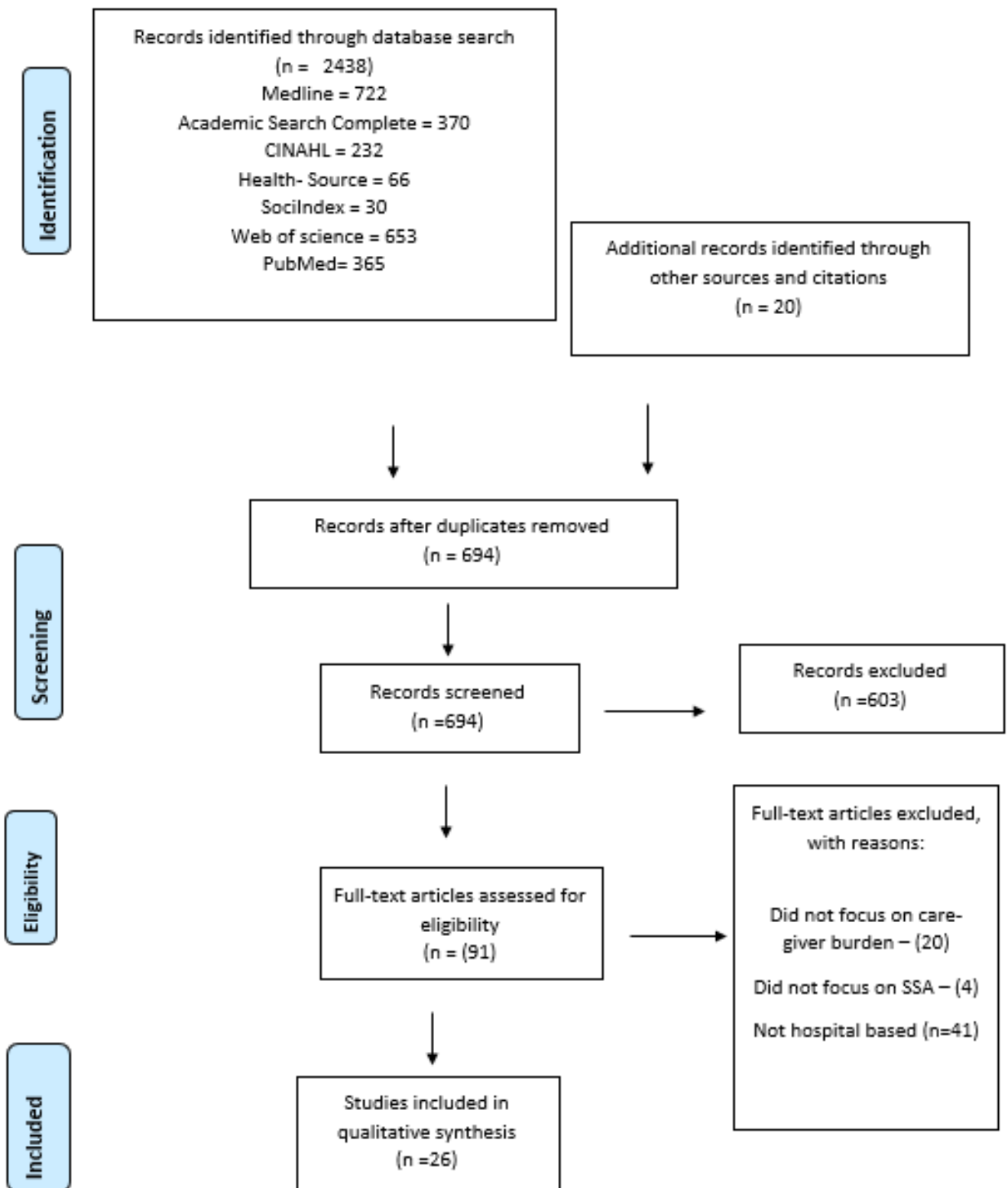


Figure 1. The PRISMA flow diagram describing the process of study selection.

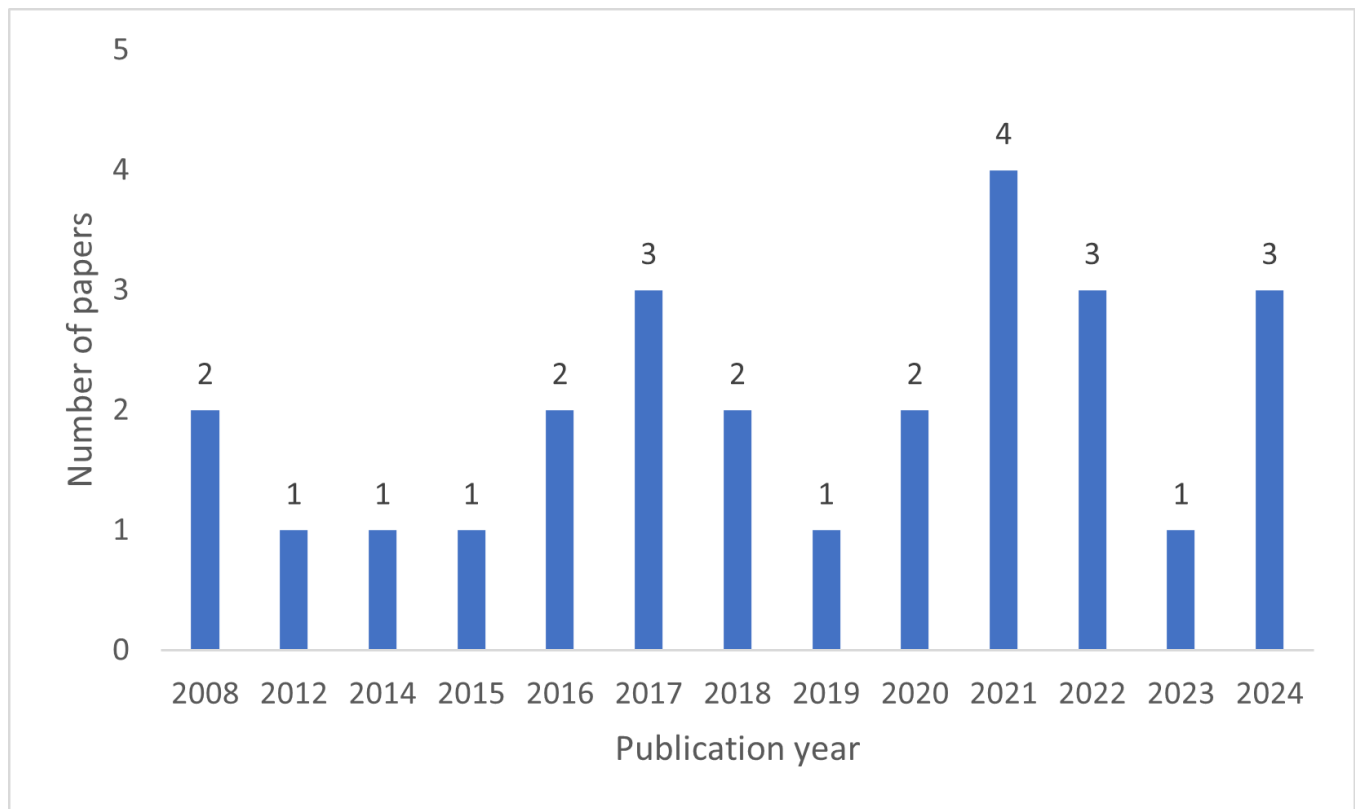


Figure 2. Published papers on hospital-based informal caregivers' burden in Sub-Saharan Africa, 2000 - 2024.

informal caregivers, emphasizing the need for targeted support [29].

Caregiving experiences and support needs are another key theme, as seen in studies documenting the lived experiences of mothers providing Kangaroo Mother Care in South Africa and the support requirements of caregivers for patients with end-stage renal disease in Rwanda. The dynamics of lay caregiving in Ghana further illustrate how caregivers navigate their roles in the healthcare system.

The burden of caregiving is quantified through evaluations of its prevalence and associations with various factors, including patient and caregiver-related variables in Nigeria, while also measuring the cost and burden of informal caregiving in relation to gender and socioeconomic status.

Lastly, some studies explored caregiver interactions with healthcare systems, assessing satisfaction with services provided to stroke patients in Nigeria and articulating the expectations of Mozambican family caregivers towards hospital care and staff [34].

The review highlights the varied definitions of caregiver burden among informal caregivers in Africa. Some studies defined burden in terms of emotional factors like anxiety, shock, and fatigue [32], while others framed it in economic terms, such as the lack of financial support [30, 35]. The studies in our review relied on various instruments, making it challenging to compare findings across different regions or countries and hindering the establishment of a comprehensive understanding of care-

giver burden. Four out of the ten quantitative studies used various scales to measure caregiver burden, including the Caregiver Burden Scale, Zarit Burden Scale, Caregiver Strain Index, and Stroke Caregiver Satisfaction Questionnaire. The diversity of tools highlights the multi-dimensional nature of caregiver burden, capturing different aspects such as emotional, economic, and physical strain. For example, a study from Uganda reported a mean caregiver burden score of 55.2 using the Caregiver Burden Scale, while in Nigeria, stroke caregivers' satisfaction was categorized into not satisfied, satisfied, and highly satisfied, with only 4% reporting dissatisfaction. Another Nigerian study using the Caregiver Strain Index found that 97.6% of caregivers of stroke patients reported being highly burdened. Economic burden also emerged as a significant theme, particularly in Ethiopia and Tanzania. In Ethiopia, 22% of caregivers experienced severe burden, as measured by the Zarit Burden Scale, while in Tanzania, the economic burden of femur fractures was quantified, with caregivers losing 9% of their annual income. Furthermore, studies focusing on end-of-life care in Johannesburg highlighted the severity of caregiver burden, with 62% of caregivers in Johannesburg reporting high burden in the final week of life.

Thematic analysis

The thematic analysis of the qualitative literature reviewed revealed different types of burdens and stress experienced by caregivers. The themes include the phys-

ical health burden of caregiving, socio-economic challenges, emotional distress and social isolation, and family strain.

Burden of care on physical health

Approximately half of the caregivers of hospitalized patients in this review frequently grappled with physical exhaustion as a predominant consequence of caring for their loved ones. Physical exhaustion resulted from activities such as assisting with bathing, feeding, and moving patients, as well as managing medical equipment, administering medications, and attending to their personal needs. Caregiving was physically demanding, because the caregivers were providing around-the-clock care, managing medications, assisting with mobility, and dealing with other caregiving tasks. This was noted in one of the studies conducted in Ghana [7]:

“I assist her to bathe. She can’t bathe on her own. In the morning, I boil water and if it means giving her a bed bath, I do or take her to the bathroom and bathe her. Can a nurse do all these for her?”

These activities sometimes led to aches and pains, as documented in another study in Malawi [36]:

“...Sometimes guardians turn their patients, and our beds are short, so they bend themselves excessively and twist their backs and end up complaining of backaches. [...]there is no place for a guardian to sit or rest, we sit on the bed where the patient is sleeping, we sleep on the floor. My whole body is very sore, and I have not slept since I came here, so it’s not an easy thing to do”

Pain, associated with the fatigue from staying in one position, was highlighted among mothers providing care to preterm babies in South Africa [37].

“It is painful to spend most of the time lying on your back in the evening. I move from bed to chair and move around like that”

In the process of compensating for the vacuum created by overcrowding, inadequate staffing, and insufficient medical supplies and equipment in the healthcare facilities, ICs found it difficult to manage their own hygiene [37]:

“One may give birth today, sleep over with the same dress and it may not be easy for me to walk around using the very same dress. I spent three days wearing the same dress but have identified a nightdress put off by someone, I took it and washed it with warm water”

Socioeconomic burdens of caregiving

There were consequences of caregiving on social lives, family relationships, finance and employment. Caregiving resulted in financial strain in multiple ways, which could be the cost of medical bills or time taken off work to care for the hospitalized patient [36]:

“... I earn a living by doing some piece work, so now that I am here with my brother, I am not earning any money to support my family”

The economic burden of providing hospital-based informal caregiving was also expressed by caregivers in Nigeria [30]:

“...the purchase of drugs and the investigations are quite expensive and it is affecting our finance, also we don’t have any relatives here so we usually buy our food. This also cost a lot of money”

Apart from the money they spent during caregiving, the time spent away from work also resulted in loss of employment or money-making activities as noted by this participant [36]:

“...I have a small shop where I sell groceries back home but now I just closed it when coming here because I could not trust it with anyone. So, it is very difficult to meet most of the needs when I am here”

This was also expressed by caregivers of patients with end-stage renal diseases in Rwanda. They felt they lost their work-life balance because of caregiving [31]:

“Before getting sick I was a businesswoman but now I can’t do that anymore because, we have been in hospital for long time, for example “last August, we were in hospital, we returned in February, and this April we are in the hospital” it is like every month we go in the hospital. I no longer do any other thing other than taking care of him. I can’t even go to pray; I just stay here”

Emotional distress

Some of the studies [7, 23, 32, 38] noted that caregiving can be emotionally taxing, and caregivers experienced a range of emotions, such as anxiety, depression, and grief. Factors such as the severity of the illness, the length of hospitalization, and the uncertainty surrounding the prognosis compounded emotional distress. For instance, one of the studies in South Africa highlighted the caregivers’ anxiety [38]:

“It is very painful to hear that because we were thinking he was going to come up and recover. . . you get worried, confused and it is really painful, it is so much stress, I am so frustrated”

The families frequently expressed these sentiments after choosing to shift to palliative care.

The relationship between the hospital staff and caregivers was also a cause of emotional distress as noted by some caregivers [35]:

“They chase us out like, ‘Go out, you’re behaving as if the hospital is your home”

Caregivers felt they needed to be present for their ill family members and did not want to leave the side of the patients.

Having to be directly involved in the care of relatives and witnessing their situation could also be a source of anxiety and fear. Caregivers in South Africa for patients receiving end of life care worried about making a mistake without proper supervision [38]:

“... you will come and she has all these things attached to her, the machines, and you are scared to touch because you think, what if I mess, what if I switch the machine off accidentally? But if I can do whatever under supervision, then it would be great”

Social isolation and Family strain

Social isolation was highlighted in less than half of the studies reviewed. It highlights the challenges faced by ICs who became socially isolated because of their caregiving responsibilities and explores the various dimensions of family dynamics that are impacted by this isolation. It encompasses the emotional and practical challenges ICs face as they provide care and the ways in which family relationships are strained or supported in these circumstances.

Not being able to participate in their usual activities resulted in social isolation for many caregivers. According to a study conducted in Nigeria [30]:

“...it has affected my going out to places ...I am not able to visit anyone, this has really constrained me and I feel like my life is kept on hold. I cannot do anything”

Similarly, a participant in the same study said [30]:

“I am not around in the house so attending all ...and ceremonies are affected. Last Saturday I was supposed to attend a wedding, but I was not able to, today I had another one, but I am here”

Some of the caregivers also suffered separation from other family members, which in turn affected their relationships. This neglect varied among caregivers. For instance, some reported being unable to give attention to their children at home, as one caregiver expressed [37]:

“Eish! I left my daughter with her father. Ever since I came to the hospital, I never went home. My 8-year-old child says she is bored since others are with their mothers, while she is not. The last time I spoke to her, she said I should come back home. This situation is frustrating me because the father gets to work by 03h30 in the morning. She remains alone at home when the father goes to work, and no one wakes her up for school”

Some ICs struggled with relationship with their spouses [37]:

“My husband is not happy about this situation which makes me to be away from home. I got this over the phone through my conversation with him because he is not staying with me at home. He is staying far away from us. Another thing is that since the babies were born, I did not go home, and it is true he did not take that well. Another thing, I have left my eldest child with the father”

DISCUSSION

Informal caregivers occupy an important role within the healthcare landscape, especially in resource-limited settings where they help mitigate the impact of staff shortages [1]. These caregivers dedicate themselves to providing essential support and care to patients. While previous studies have shed light on various aspects of informal caregiving worldwide [2-5], our scoping review addresses a pressing need to explore the unique burdens and challenges faced by individuals providing hospital-based informal caregiving in African settings. Understanding these aspects is crucial for developing targeted interventions and support systems that can enhance the well-being of caregivers, improve patient outcomes, and contribute to the overall effectiveness of healthcare delivery in the region.

Our findings reveal variability in measurement tools and definitions of burden. These tools—ranging from the Caregiver Burden Scale, the Zarit Burden Scale, the Stroke Caregiver Satisfaction Questionnaire, to the Caregiver Strain Index—reflect different dimensions of burden (emotional, economic, physical). While some studies focused on subjective caregiver experiences (e.g., satisfaction or strain), others quantified burden based on objective measures like economic loss. This variation complicates comparisons across studies but highlights the multi-dimensionality of caregiver burden, demonstrating how the construct of “burden” is multifaceted and context-dependent.

Key findings from this review highlight the physical health burden, socioeconomic challenges, emotional distress, social isolation, and family strain associated with informal caregiving in African hospital settings. The findings from our scoping review contribute to the broader literature on informal caregiving, aligning with existing research that highlights the substantial physical burden endured by caregivers [39]. Similar studies conducted in various global contexts have identified common themes, emphasizing the pervasive challenges faced by individuals providing informal care to hospitalized patients [12]. The shared experiences of physical exhaustion, aches, and fatigue underscore the universal nature of caregiver strain across diverse caregiving settings [40, 41].

These insights hold significant implications for policy and practice in healthcare. Firstly, policymakers need to acknowledge the unique challenges faced by hospital-based informal caregivers in African settings

and consider incorporating targeted support measures into healthcare policies. Such measures may include the provision of respite care, and the implementation of flexible work arrangements to accommodate caregivers' needs. Globally, there is growing concern for the well-being of informal caregivers. Efforts are being focused on creating respite care programs that offer support and relief by temporarily alleviating the caregiver's responsibilities [42]. Although this has not yet been documented in African settings, countries like Canada, with an aging population and increased caregiver burden, have demonstrated the feasibility of respite care [43]. Additionally, a review of existing interventions has shown that strategies designed to enhance caregivers' skills and confidence can lead to safer and more effective care. One of this intervention includes teaching caregivers how to manage specific patient problems [44, 45]. Such improvements can alleviate caregiver distress by reducing their workload or increasing their sense of certainty and control [46]. Some other interventions such as support groups or education [47, 48] and, counselling [49] have also been shown to reduce burden among informal caregivers.

In terms of practice, healthcare professionals should be sensitized to the physical toll on caregivers and play a pivotal role in identifying and addressing their needs. Integrating caregiver support programs within healthcare institutions, such as counseling services, educational resources, and peer support groups, can contribute to mitigating the physical burden experienced by caregivers [50].

Additionally, these findings emphasize the importance of a multidisciplinary approach to caregiving. Collaborative efforts involving healthcare providers, social workers, and community organizations can facilitate a holistic support system for caregivers [51, 52]. By recognizing and addressing the physical strain experienced by caregivers, healthcare systems can enhance the overall quality of care provided to patients while fostering the well-being of those who play a crucial role in the caregiving process.

Hygiene maintenance is clearly a significant challenge for caregivers, who often struggle to manage their own hygiene due to the demands of caregiving. This issue highlights the need for healthcare policies to recognize and support caregivers based on their important role within the health system. Addressing caregivers' difficulties with hygiene and nutrition can help create a more sustainable caregiving environment and improve patient care. Hospitals should provide dedicated spaces, such as rest areas or lounges, equipped with amenities like toilets, information resources, and quiet areas for relaxation [52, 53]. These facilities can help caregivers maintain their well-being, reduce stress, and enhance their ability to support patients effectively.

Two studies focus on the economic burden of caregiving, both highlighting significant financial strain. The study in Tanzania reports an average economic burden

of \$149 and a 9% loss in annual income for caregivers of patients with femur fractures, emphasizing the heavy financial toll of caregiving in low-income settings. Similarly, the Ethiopian study highlights that 22% of caregivers experience severe economic burden. These findings emphasize the need to consider economic support systems in policy and intervention planning, particularly in low-resource settings where caregiving can disproportionately affect household income. The economic complications arising from hospital-based informal caregiving, and their effects on carer mental and physical wellbeing, have been established in other settings. For instance, caregivers in the United States with financial strain showed worse mental health than those with no financial strain. Female or adult children caregivers reported significantly less time walking, more financial strain, and a higher level of negative mental health outcomes compared to male or spouse caregivers [54]. Policymakers need to recognize the financial strain experienced by caregivers and consider implementing measures to alleviate this burden. This may involve financial assistance programs, insurance coverage for caregivers, or tax incentives to offset some of the caregiving-related costs. Additionally, healthcare policies should integrate support mechanisms to mitigate the economic impact, such as providing information on available financial resources and assistance programs [55]. In practice, healthcare professionals should be equipped to guide caregivers toward available financial support services and offer information on strategies to navigate the economic challenges associated with caregiving. Acknowledging and addressing the economic implications of caregiving is crucial for creating a supportive environment that ensures the financial well-being of caregivers, allowing them to provide quality care without jeopardizing their own long-term financial security. Moreover, employers and businesses can play a role by implementing flexible work arrangements and policies that support caregivers in maintaining a balance between their caregiving responsibilities and professional commitments. This type of flexible work arrangement has been documented among carers in New Zealand [56]. This holistic approach can contribute to a more sustainable caregiving landscape, safeguarding both the economic stability and overall well-being of informal caregivers in hospital settings.

The emotional challenges faced by caregivers, as shown in our study, hold particular significance within the context of African settings. Policymakers in the region should recognize the unique cultural aspects that influence emotional well-being and incorporate culturally sensitive mental health support services into healthcare policies. This may involve promoting community-based support systems, engaging local mental health resources, and integrating traditional healing practices where appropriate. Additionally, healthcare policies should emphasize the importance of collaborative and empathetic relationships between hospital staff and caregivers, tak-

ing into account cultural nuances and preferences. In practice, healthcare professionals should receive cultural competency training to better understand and respond to the emotional needs of caregivers in African settings [57]. This has worked in other settings like Canada. This approach has proven effective in other contexts, such as Canada [58]. Creating spaces within healthcare institutions that respect and incorporate cultural practices for emotional support can further enhance the effectiveness of caregiving support. By addressing the emotional toll in a culturally sensitive manner, policies and practices can contribute to a more holistic and contextually relevant caregiving environment, ultimately improving the emotional well-being of caregivers and the overall patient care experience in African settings.

The challenges of social disengagement and disruption of usual community participation reveal the profound impact of caregiving on caregivers' social lives. This echoes existing literature on informal caregiving, underscoring the universal nature of the social isolation experienced by caregivers across diverse cultural contexts [59, 60]. Family separation and strain further compound the caregiving journey, emphasizing the complex associations between caregiving responsibilities and familial relationships. The experiences of separation from children and strain within spousal relationships are consistent with broader literature on the social implications of caregiving [59, 61, 62]. It is crucial to recognize the heterogeneity in caregivers' experiences of challenges and the resources they have available to face these.

The complex interplay of various dimensions of the caregiving burden in African settings unveils interconnected challenges and potential causal relationships. The physical strain on caregivers and its associated health implications can have profound effects on mental well-being. The constant engagement in physically demanding activities may contribute to heightened stress and emotional fatigue. Conversely, compromised mental health, exacerbated by emotional distress and social isolation, can reciprocally impact physical well-being, creating a cyclical relationship between the two dimensions. Additionally, the effects of compromised social interaction and isolation may further intensify mental health challenges for caregivers. The lack of a robust support system and social engagement can contribute to feelings of loneliness and emotional exhaustion, exacerbating the overall burden on caregivers [39, 63, 64]. Recognizing these interconnected dimensions is essential for developing comprehensive interventions that address the holistic well-being of caregivers, considering the potential combined effects of physical health on mental health and vice versa, as well as the broader implications of compromised social interactions. Policymakers and healthcare practitioners should adopt a multifaceted approach that acknowledges and addresses these interrelated burdens to provide effective and targeted support for caregivers in African settings.

Our review begins by providing a clear definition

of caregivers, individuals without formal health training who offer critical care and support to patients, typically including close family members [6]. Notably, the predominance of female caregivers aligns with cultural norms that often assign women the role of family caregivers, reflecting long-standing norm-based socialization processes [65, 66]. The finding that the majority of caregivers in the studies reviewed are female highlights important considerations for caregiving and healthcare. While the studies reviewed may not fully capture the diversity of caregiver age, existing statistics on caregivers suggest a wide age range [67-69], which has implications for caregiving support. First, this underscores the need for a gender-sensitive approach in caregiving support programs, recognizing the unique challenges faced by female caregivers. Health policies and interventions should be designed to account for the gendered aspects of caregiving, providing targeted resources and support to alleviate the potential strain on female caregivers. Additionally, healthcare practitioners should be mindful of the varying needs and preferences across different age groups, as age-specific challenges can affect the type of support caregivers require.

Most of the patients being taken care of by caregivers in our review studies were adult patients who had cancer or stroke. This underscores the need for targeted support programs tailored to the unique challenges associated with caring for individuals with chronic and debilitating illnesses. Caregivers of cancer patients, for example, may require specialized training in managing the physical and emotional aspects of cancer care, including side effects of treatments and end-of-life care considerations. Similarly, caregivers of stroke patients may benefit from education on rehabilitation techniques and long-term care strategies.

Limitations

Throughout the course of this scoping review, we encountered several limitations that warrant thoughtful consideration. Our decision to employ an English language limited in our search strategy may have inadvertently excluded pertinent studies published in languages other than English. This linguistic constraint is a common challenge in scoping reviews and raises the possibility that valuable insights from non-English publications may have been omitted from our analysis.

Our scoping review took an inclusive approach by not limiting the type of diseases studied. While this allowed us to cover a broader range of conditions, it also introduced diversity in the study populations and outcomes, making it harder to draw specific conclusions related to individual diseases. This could have led to an uneven focus on caregivers of patients with certain conditions. The diversity in the operationalization of caregiver burden may impact the robustness of the synthesized insights and could constrain the precision of our conclusions.

Considering these limitations, it is imperative to in-

interpret the findings of this scoping review with caution. We acknowledge that there may exist a subset of relevant studies, including non-English publications, older literature, and context-specific investigations, that were not encompassed within our analysis.

Conclusion

This scoping review deepens our understanding of the burdens, challenges, and methodological considerations in the field of hospital-based informal caregiving in Africa. As such it sets the stage for further research and policy development in this critical area of healthcare. The unique challenges faced by informal caregivers in African hospital settings demand specific attention within the caregiving literature and should guide future research, interventions, and support systems tailored to the needs of this particular group of caregivers in this region. Policymakers should recognize caregivers' indispensable role, integrating support measures into healthcare policies to address financial strain, enhance well-being, and promote equitable caregiving. Healthcare practitioners must be attuned to the important role and needs of these caregivers and be better empowered to interact with them positively and offer appropriate support. Furthermore, acknowledging and addressing the emotional toll on these individuals – mainly women – in a culturally sensitive manner is vital, promoting family and community involvement to mitigate social isolation. This comprehensive understanding is crucial for the development of effective policies and practices that not only acknowledge the challenges but also enhance the resilience and well-being of informal caregivers in African healthcare settings.

Future Research

All the studies we reviewed predominantly focused on caregiver burden and its associated negative consequences. This highlights the need for future research that delves into coping strategies, resilience, and support mechanisms employed by informal caregivers in Africa. Insights into effective coping mechanisms, as derived from our findings, can guide the design of interventions and support programs specifically catered to the distinctive needs of caregivers.

Moreover, our analysis revealed a noticeable underrepresentation of certain caregiver groups in the reviewed studies, particularly male caregivers and young caregivers. The incorporation of a diverse array of caregivers is crucial, as it has the potential to unveil unique challenges that might otherwise remain overlooked. This recommendation retains its relevance even considering the acknowledgment that women bear the primary burden of hospital-based informal caregiving. While recognizing the essential task of addressing the burden and support needs of women in caregiving roles, it becomes imperative to broaden our perspective to include the more specific, yet at times neglected, minority groups of caregivers. In acknowledging the substantial caregiving burden on women, the breadwinners' role

of male caregivers or unique situations of people from marginalized communities in Africa may pose distinct challenges requiring targeted attention. Neglecting the unique situations and support requirements of these caregiver groups risks perpetuating inequalities within caregiving dynamics. More inclusive research and programs would work towards a more equitable and encompassing caregiving support framework that meets the specific needs of all caregivers, fostering a holistic and effective system of assistance.

Also, most of the caregivers in these studies were caring for cancer or stroke patients. Future research should aim to include a broader range of caregiver populations in terms of the type of condition or situation of the individual cared for, and/or focus on some of these more specific groups of caregivers. These may include individuals caring for disabled children and pregnant women in hospital settings. These groups of caregivers may face unique challenges that are not fully understood or documented in the current literature.

From a methodological perspective, many of the quantitative studies included in our review featured small sample sizes. Given the diverse cultural, socioeconomic, and geographic contexts across Africa, larger and more representative samples are essential to capture the full spectrum of caregiving experiences and challenges and improve the generalizability of findings. Furthermore, none of the qualitative or mixed methods studies used ethnographic approaches or group-based techniques, such as focus group discussions, which may have allowed for a shared understanding of perceptions and norms shaping experiences of the burdens and challenges reported in the studies. Also, a participatory approach was absent, even as methods such as photovoice have increasingly been shown as promising in health research [46].

We would also suggest that future research include studying ICs as key health systems actors – to explore both how this reality may shape their experiences of burden and challenges and how their presence and role may shape the health care and health system dynamics. This would require better understanding their hospital-based informal caregiving life, and possibly engaging with a range of other stakeholders within the healthcare facilities and system, as well as with caregivers. This line of research would likely provide us with further evidence-based appreciation of the challenges and value of these caregivers as a unique group of individuals contributing to patient care in African health systems settings.

DECLARATIONS

Publication Consent

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Competing interests

No conflict of interest to declare.

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Author contributions

Kudus Oluwatoyin Adebayo: Conceptualization, funding acquisition, investigation, methodology, resources, and writing – review and editing. Oluwaseyi Dolapo Somefun: Conceptualization, investigation, methodology, resources, and writing – review and editing. Mofeyisara Oluwatoyin Omobowale: Investigation, resources.

Rukayat Usman: Investigation. Marisa Casale: Methodology, resources, and writing – review and editing. Adebayo Emmanuel Akinyemi: Investigation.






Data availability

The referenced materials are all publicly available.

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Cargas y desafíos del cuidado informal hospitalario en África: Una revisión de alcance

RESUMEN

Introducción: Los cuidadores informales (CI) desempeñan un papel fundamental en la asistencia sanitaria, especialmente en entornos con recursos limitados, donde contribuyen significativamente a mitigar la escasez de personal. A pesar de su invaluable aportación, la literatura sobre los desafíos que enfrentan es insuficiente. Esta revisión sistemática se propone llenar este vacío, explorando las cargas y desafíos específicos que enfrentan los cuidadores informales en contextos hospitalarios africanos, reconociendo las dificultades particulares de estos entornos.

Métodos: Esta revisión de alcance fue realizada incluyendo literatura desde el año 2000 hasta 2024, enfocándose específicamente en contextos hospitalarios africanos. Se realizaron búsquedas en bases de datos como Web of Science, Medline, PsycINFO, SociIndex, CINAHL, Africa-wide, Academic Search Complete y PubMed. La selección inicial se basó en la relevancia de los resúmenes, y dos autores revisaron los textos completos de los estudios potencialmente relevantes. Los artículos fueron incluidos según los siguientes criterios: (1) describen las cargas y el estrés que experimentan los cuidadores informales; (2) se enfocan en investigaciones llevadas a cabo en África; (3) están publicados en inglés; y (4) fueron publicados entre el 1 de enero de 2000 y el 31 de agosto de 2024.

Resultados: Se incluyeron 26 estudios pertinentes, con la mayoría realizados en Nigeria (n=6), seguidos por Sudáfrica y Uganda (n=4 por país). Trece estudios utilizaron métodos cualitativos, diez aplicaron métodos cuantitativos y tres utilizaron enfoques mixtos. Los métodos cualitativos predominaron, basándose principalmente en entrevistas, aunque con un uso limitado de métodos etnográficos o técnicas de grupo como grupos focales. Los roles de cuidadores fueron asumidos comúnmente por miembros de la familia, incluyendo cónyuges, padres, hermanos y otros parientes. Los temas identificados incluyen la carga física del cuidado, desafíos socioeconómicos, angustia emocional, aislamiento social y tensión familiar.

Conclusiones: Esta revisión de alcance proporciona una visión valiosa sobre un aspecto poco estudiado de la asistencia sanitaria en África, destacando los desafíos a los que se enfrentan los cuidadores informales. Al abordar esta brecha de conocimiento, se establecen las bases para futuras investigaciones, el desarrollo de políticas y la implementación de intervenciones que apoyen a los cuidadores informales en los entornos hospitalarios africanos.

Palabras clave: Africa; basado en el hospital; informal; cuidado; hospitalización; cuidadores; carga.

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