INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH AND WELL-BEING
2024, VOL. 19, 2356928
https://doi.org/10.1080/17482631.2024.2356928

Taylor & Francis
Taylor & Francis Group

"I am the one taking care of her and donating blood": lived experiences of role-routines of hospital-based informal caregiving in Nigeria

Kudus Adebayo [a,b], Mofeyisara Omobowale [c], Adebayo Akinyemi[d], Rukayat Usman[a], Atinuke Olujimi[e] and Funmilayo Omodara[c]

[a]Institute of African Studies, University of Ibadan, Ibadan, Nigeria; [b]School of Public Health, University of The Witwatersrand, Johannesburg, South Africa; [c]Institute of Child Health, College of Medicine, University of Ibadan, Ibadan, Nigeria; [d]Department of Sociology, Osun State University, Osogbo, Nigeria; [e]Department of Sociology, University of Ibadan, Ibadan, Nigeria

ABSTRACT

Purpose: Informal caregivers (ICs) in Africa perform a long list of tasks to support hospitalization care. However, available studies are weak in accounting for the experiences of everyday role-routines of hospital-based informal caregiving (HIC) in under-resourced settings. This article explored the experiences of role-routines among informal caregivers in a Nigerian tertiary health facility.

Methods: The ethnographic exploratory study relied on primary data collected from 75 participants, including 21 ICs, 15 inpatients, 36 hospital staff, and 3 ad-hoc/paid carers in a tertiary health facility in Southwestern Nigeria.

Results: ICs perform several essential roles for hospitalized relatives, with each role characterized by a range of tasks. An integrative narrative of everyday routines of HIC as experienced by ICs showed critical complexities and complications involved in seemingly simple tasks of assisting hospitalized relatives with hygiene maintenance, medical investigations, blood donation, resource mobilization, errand-running, patient- and self-care and others. The role-routines are burdensome and ICs' experiences of them revealed the undercurrents of how health systems dysfunctions condition family members to support hospitalization care in Nigeria.

Conclusion: The intensity and repetitive nature of role-routines is suggestive of "routinization of suffering". We recommend the closing of gaps driving hospital-based informal caregiving in Africa's under-resourced settings.

ARTICLE HISTORY
Received 10 October 2023
Accepted 14 May 2024

KEYWORDS
Care burden; health system; informal carers; inpatient care; human resource for health

Introduction

The roles performed by informal caregivers (ICs) have been a topic of scholarly investigations in different settings (Agbenyefia, 2017; Alshahrani, 2016; Angood et al., 2010; Asuquo & Akpan-Idiok, 2020; De Silva, 2020; Donelan et al., 2002; Hoffman et al., 2012; Khosravan et al., 2014; Muliira et al., 2019; Nkuranyabahizi et al., 2021; Shields et al., 2018; Stavrianou et al., 2018). In Africa, it is agreed that their roles in supporting the formal health system cannot be relegated (Hoffman et al., 2012; Sabo et al., 2022). Studies show, for instance, that ICs perform a long list of tasks, which can range from simple to complex, especially when such roles are performed in the context of hospitalization (Hoffman et al., 2012; Hogan et al., 2022). However, available studies are weak in accounting for how these roles are carried out and experienced, as well as the complexities that shape their performance in under-resourced health system settings. Moreover, existing studies have taken little interest in disaggregating ICs population towards uncovering how the context of hospital-based informal caregiving (HIC) determines the experiences of those supporting hospitalization care in Africa. This study addressed these gaps in informal caregiving literature by documenting the roles and experiences of role-routines of HIC in Nigeria.

Informal caregiving is an essential component of global health care provision. It is basically the kind of unpaid care provided at home or in a hospital facility by family members to sick relatives (Chukwu et al., 2022). Globally, there are notable variations in the motivations, experience, performance and challenges of informal caregiving (Chukwu et al., 2022; Okoye, 2012; Vincent-Onabajo et al., 2013). Oyegbile and Brysiewicz (2017) and Hogan et al. (2022) assert that motivations vary between high-income and low-income countries, and can be partly explained by contextual factors connected to cultural and institutional diversity. Accordingly, Zarzycki et al. (2023, p. 1583) note, following a systematic review of 84 empirical studies on the motivations for caregiving, that "people's motivations for caring are underpinned by specific cultural values." These values manifest across cultures as principles of filial piety, familism, reciprocity and many others (Muoghalu & Jegede, 2010; Okoye, 2012; Oyegbile & Brysiewicz, 2017; Yiu

CONTACT Kudus Adebayo oluwatoyinkudus@gmail.com Institute of African Studies, University of Ibadan, Room 3, Ibadan 200005, Nigeria

et al., 2021; Zarzycki et al., 2023). While these principles are culturally significant in motivating care act, contextual factors like the geographical distance of patients to caregiver, status or life stage of caregiver, severity of illness and suchlike also influence motivation to care (Bei et al., 2021).

Still, the roles ICs and practices of informal caregiving can vary, reflecting differences in cultural norms, familial structures, and levels of sophistication of healthcare systems. In hospitalization situation especially, ICs play wide-ranging roles to support sick relatives. As Komuhangi et al. (2022, p. 22) identified, ICs' "roles include counselling, administering medication, supporting logistics around hospital appointments; doing day-to-day household tasks like cooking, washing clothes, shopping; and providing social support and companionship". They provide instrumental assistance related to food, laundry, managing errands, providing money for services and supporting the sick emotionally (Amoah et al., 2018). In performing caregiving roles, however, ICs face numerous challenges.

Studies highlight challenges related to lack of sanitation facilities, exposure to mosquito bites, infection, and exposure to environmental discomfort of heat in the daytime and excessive cold of the night, lack of beddings and seats in the process of HIC (Agbenyefia, 2017; Gambe et al., 2023; Komuhangi et al., 2022). Further, they identified issues like the proximity of toilet facilities to beds, lack of privacy and infection control, hostility, stigma, and discrimination. Also, their sheer presence has been shown to obstruct formal care while exposing ICs to health vulnerabilities (Alkali, 2019; Alshahrani, 2016; Amoah et al., 2018; Donelan et al., 2002; Hilton et al., 2013; Hoffman et al., 2012; Sadigh et al., 2016). Discomforting hospital environment and reliance of formal health workers on ICs to attend to patients also contribute to the challenges they experience (Alkali, 2015; Chukwu et al., 2022). Informal caregiving is also recognized as a source of economic problems at individual and national levels since ICs involved in HIC are often unable to go to work while stuck in the health facility to support hospitalization care (Legese et al., 2020; Sadigh et al., 2016; von Kaeppler et al., 2021). Studies conducted in Nigeria show that ICs face burdens at an elevated level, which contributes to their being at risk of depression (Akosile et al., 2018; Okeke et al., 2020).

Clearly, HIC as performed by relatives of inpatients is an integral part of hospitalization care in Africa today. In Nigeria in particular, the healthcare system has relied heavily on informal care structures due to several factors, such as chronic underfunding, a shortage of health professionals, and inadequate healthcare facilities (Abubakar et al., 2022; Kipp et al., 2007). The shortage of health professional has worsened the care situation due to skilled labour migration in the health sector (Ahmad, 2023; Oyeleke, 2023; Yakubu, Blacklock, et al., 2023; Yakubu, Shanthosh, et al., 2023). Consequently, HIC has become an essential part of hospitalization care in many public tertiary health facilities. However, there is limited understanding of how ICs experience the role-routines associated with HIC and the complexities involved towards health systems adaptation in under-resourced setting.

The present article closes an important research gap in African health system studies by focusing on the experiences of migrating informal caregivers (MICs), that is, a sub-population of ICs who travel far away from home to serve as caregivers to inpatients and are subsequently stationed in/around health facilities. While documenting the various roles played by ICs, we further show the complicated nature of the roles as experienced in the everyday performance of HIC in Nigeria. In doing this, we go beyond role checklist and cultural norms shaping care motivations to reveal the undercurrents of systematic health systems dysfunctions that condition family members to support the care of hospitalized relatives. Through ethnographic methods, this article advances discussion on the growing practice of HIC and makes recommendation towards improving the wellbeing of ICs supporting the care of hospitalized relatives in Africa. In the next section, we present the methodology of the study that produced the article. This is followed by sections on the presentation of empirical findings, critical discussion of evidence and then conclusion.

Materials and methods

The article is part of the findings from an ethnographic exploratory research which focused on the lived experiences of MICs in a Nigerian tertiary health facility. It adopted qualitative techniques, such as observation, in-depth and key informant interviews and photovoice, for data collection in a public tertiary health facility in southwest Nigeria. We interviewed various categories of participants in the wards, offices, public spaces, corridors, restaurants, restrooms, and other sites within and near the hospital community. Non-probability sampling approach was used to select and interview 75 participants (see Table I).

The participants were selected using purposive, snowballing, quota and convenience sampling approaches. We approached caregivers inside and around hospital wards to casually inquire about their reason for being in the facility, after which we introduced the study and invited them to voluntarily participate. Inpatients were approached after securing necessary ethical and hospital approvals and consent of patients. Quota sampling was further used to ensure that study population is diverse, based on factors such as age, gender, socioeconomic status, and, especially, the nearness of their place of normal residence to the health facility. The snowballing technique was particularly useful in identifying

Table I. Study population by distribution of interviewees and average interview duration.

	Study population	IDI	KII	Average interview time (in mins.)
1	Caregiver	21	-	43
2	Inpatient	15	-	33
3	Hospital staff			
	• Management	-	6	
	• Nurse	-	10	35
	• Doctor	-	5	23
	• Security guard	-	5	26
	• Health assistant (ward)	-	5	34
	• Health assistant (environment)	-	5	24
4	Ad-hoc/paid caregivers	-	3	13
	Sub-total	36	39	
	Total	75		

relevant units and departments of the hospital. Convenience sampling was further employed to select participants based on considerations such as inclusion criteria, availability and willingness to participate. All the participants were interviewed face-to-face.

To be included in the study, formal employment in the health facility was required for hospital staff while ad-hoc caregivers were qualified to participate based on their affiliation and role. Inpatients were included if they were on admission and receiving care in any of the inpatient wards, have an informal caregiver on-site who came from outside the city to support their care, can speak and subjectively able to participate. Finally, an IC was qualified to participate if their usual residence was located outside the city where the hospital is situated; was attending to an inpatient admitted in the past three days or more; resided or have resided in/around the healthcare facility during data collection, and; of any gender and aged 13 and above.

Socio-demographically, the ICs in the study were predominantly females (71%), with the majority being aged 35–44 (29%), followed by those aged 55–64 (19%). Most of them had secondary education (43%), were married (76%), and from a nuclear family (67%). Fourteen caregivers or 67% were informally employed and 38% earned ₦50,000 or less monthly (or $110 or less in January 2023 when data collection started). The age range of their care recipients varied but most were females (52%). The caregivers were largely parents (48%), but all were relatives of the patient. In terms of residence, caregivers in the study mainly resided outside the state—or province—where the healthcare facility is located (62%) and 86% of them have been living in/around the hospital for more than a week when we interviewed them.

Conversely, most the hospitalized patients were females (60%), with those 44 years and below accounting for 67% of the total. More than half of inpatients or 53% were formally educated to the tertiary level. Also, 73% reported being married and 93% were from nuclear families. Those formally employed constituted the majority (40%), and most (47%) did not offer information on monthly income. They also reported that their caregivers were predominantly women (or 73%). However, more of these caregivers, from inpatient information, were their spouses (47%) and their ages were diverse. They also reported that all their caregivers were relatives, except one person who was getting support from a co-worker. Lastly, 87% of the patients came to seek care at the healthcare facility from outside the state, with 73% having been on admission for over a week. The key informants too were largely females (60%), but the majority were aged 35 and above with high educational and professional qualifications. They also work in a wide range of wards in the healthcare facility.

The languages of interview were English, Yoruba and Pidgin English. All research team members are competent users of the three, but the participants made the final decision on the language of interview. We recorded all the interviews on audio recorders and took notes. Interview time per participant group averaged between 13 (ad-hoc/paid caregivers) and 43 (ICs) minutes. All notes from observations, daily meetings and field reports to ethnographic analysis and transcribed the interviews in the original language of conversation were back translated to English as applicable and imported into the NVivo software for thematic analysis—following the procedure outlined by Braun and Clarke (Braun & Clarke, 2006). We prepared a preliminary coding structure using the deductive approach. Extracted sections of the interviews across participants have been presented either as summaries or direct quotes in the findings section.

Finally, UI/UCH Ethics Committee of the University of Ibadan reviewed and approved the study with approval no. UI/EC/22/0317. We also obtained two additional official permissions: first from the hospital management to collect data in the hospital community and second from the head of nursing to access the wards and speak to hospitalized patients. Written and verbal informed consent were obtained from all participants. The consenting process and interviews were conducted in a language the participants preferred. Completed informed consent forms were kept at secured locations, physical and virtual, while

interview recordings, transcripts and photos were secured online and offline.

Results

Narrating role-routines in hospital-based informal caregiving

Informal caregivers perform several roles that are essential in caring for hospitalized patients. These roles ranged from errand running to caring for patient, resource mobilization, administration-related and general support. Errands running involves purchasing of drugs, injections, and other consumables, buying food, making payments and others. Tasks such as routine and general care, like investigations, personal hygiene, serving as reminders to nurses on care tasks, assisting with vomit and disposal, and blood donation fall within the remit of patient care. Resource mobilization is simply finding/soliciting money to support hospitalization care while administrative roles cover matters such as sharing patient medical information with healthcare workers, extracting cooperation of patients, intermediating in administrative matters, like National Health Insurance Scheme (NHIS) documentations, and consenting decision-making. The last role, the provision of general support, which participants called *àdúròtì*, relates to the idea of "standing by someone."

However, beyond the checklist of roles played by ICs, how they experience these roles as part of the routinized condition of their presence in the hospital is even more important. This section presents an integrative narrative based on individual everyday routines regarding the performance of HIC as experienced by ICs. The picture that emerged from ICs' narratives shows the complexity of role-routines and reveals the burdensome character of the lived experiences of informal caring in a Nigerian public health facility.

Waking up and cleaning up

Between 3 AM and 5AM, caregivers begin to emerge one by one from the ward corridors. They go towards the accident and emergency section of the hospital where other ICs had slept through the night. Near the same section of the hospital, an old woman, in her late 60s or early 70s, stood up from the iron bench she slept all night. She changed her clothes and brought out two medium buckets, folded the cloths she just changed into and puts them in one bucket. There was also a young boy of about 8–10 years-old still sleeping next to her. She woke him up, removed his trouser and pant, then proceeded to a black tank near the ward building where they collect water, after which they find a place to bathe and wash clothes.

There is no bathroom facility available to ICs. Because of this, some of them do not bathe for days. Those who manage to bathe do it outside. Bathing can be a partial or full body wash, the example of the former being to " … just rinse our arms and legs" (MIC16, female, 18). For full body wash, security guards sometimes recommend where bathing can happen to ICs who are not too familiar with the hospital environment. On their own too, ICs sneak into corners, behind big power generator or diesel tank or anywhere they can find a cover. Ultimately, however, the dark provides most of the cover. There is no privacy as women and men crouch and take bath in turn, naked but relying on the darkness to shield them. A participant told a story of a hospital worker who comes around with a torch in hand about the same time that women have their bath. He stopped coming after the women screamed on him one midnight. Happening simultaneously include brushing of teeth, washing of cloths and urinating in the open.

Still, some ICs convert available toilets into bathrooms. Although health assistants try to prevent repurposing the toilets for bathrooms; caregivers similarly try to look out for the best opportunity for bathing in the toilet. An interviewee who routinely repurpose toilets said, "I have to wait till evening again because those cleaners … might not allow you to bathe in the toilet … " (MIC18, female, 38). Health assistants labelled the facility conversion as irresponsible because ICs leave a pool of stagnant water behind and clog the drainage with plastic bags and local sponge. Besides, finding bucket to bathe can be difficult. Many of ICs sleeping in the hospital did not come to the health facility with buckets to collect water. When asked where they get buckets, one participant said " … we see it downstairs where I do bathe. Once I see a bucket, I just carry it" (MIC02, female, 37). Some borrow buckets from co-caregivers or take from the restrooms. The cleaning staff complained that their buckets go missing as caregivers take but often fail to return them. This leads to conflict between caregivers and cleaning staff. The conflict is in addition to the fear that the use of buckets from restrooms predisposes caregivers to cleaning chemicals and germs which are dangerous to human health.

In very few instances, however, some ICs wait until arriving in the wards to sneak into patient's bathroom. A participant who did this said she waited for all the patients to be done before taking her bath, although without the permission of nurses. "I did not tell them…Because if you tell them they may not allow you" (MIC14, female, 65). While exposing ICs to health hazards, their surreptitious use of patients' bathrooms poses health risks to inpatients as well.

Taking position: role-routines inside and outside the ward

Informal caregivers arrive in the ward early and wait until they can come in, between 7 AM to 9 AM. The time-in can vary from ward to ward and sleeping near the wards makes early arrival easy. However, health workers can send them away from the ward when ICs attempt to enter the ward outside official visiting hours, especially if the wards needed cleaning, if health workers are conducting ward round, or to prevent rowdiness. Nonetheless, as described next, early entry into the wards enables ICs to perform several roles, like bringing food, helping inpatients to bathe, providing hygiene assistance, and updating information and acting on new drugs request from doctors, carrying out tests and other errands scheduled for patient care overnight.

Hygiene maintenance and general patient care

Bathing of incapable patients should ordinarily be the job of health assistants or any support/care staff. However, the management and nurses complained that the hospital is chronically short of this category of staff. Hence, relatives take up the responsibilities of bathing for some inpatients. Inside the ward, bathing of relatives could be the first thing ICs attend to. " … We can do bed bath for him sometimes", noted an IC (MIC07, female, 65). An inpatient also said, " … when I was still unconscious, she used to bathe for me" (HP09, female, 23). Asides bathing, ICs help inpatients to pass faeces, and urinate, but the intensity may differ from caregiver to caregiver. For instance, one IC mentioned that his mother, who is terminally ill with cancer, " … can urinate like three … four times within 20 minutes" (MIC21, male, 38). In rare cases, ICs reported practicing simple manoeuvres to help their relatives release faeces, like the woman quoted next:

> When I first got here, the pain was so much. She has not defecated since I came. We asked what they could give her so that she could defecate, they kept trying and prescribed different drugs, but she did not defecate. … I was looking at the stool from her anus, but it did not come out. So, I took socks, two hand gloves and I put it in her butthole. … In the evening again, I did it, she felt relieved again. The next morning, I did it again and it was like two days ago she now defecated in the evening of the day before yesterday, and she has not defecated again since then … I did it by myself. Even the nurses were not there when I did it. (MIC17, female, 53)

Some ICs assist with hygiene maintenance voluntarily, because they wish to do or feel that healthcare workers are not patient enough. However, some ICs feel constrained to help, including those who lack the physical strength to offer such assistance, thus relying on the assistance of other ICs to support their sick relatives. For instance, an elderly woman said:

> You see when daddy [i.e., her husband] wanted to sit on the toilet seat, you know that … we are females, there is little we can do, if I tell you that it is that brother [another caregiver present near the ward at the time] that backed daddy on his neck and put his butt on that toilet seat … (MIC07, female, 65)

In any case, from morning and throughout the day, they partake in ensuring that their relatives are comfortable in the ward, laying their beds, using hand fan to blow them when there is power outage, moving furniture about as needed and arranging their bedsides. They talk to care recipients to make them cheerful and lively, and give them hope by staying with them and helping them get through the day.

The medical investigation maze

ICs facilitate the conduct of investigations in a timely fashion while navigating the maze of medical investigation. This maze involves ICs handling specimen bottles, making payments, taking samples to the labs and returning there to collect the results. Navigating the maze is complicated for a lot of caregivers, although many of them adjust as they spend more days and weeks in the health facility. Describing the operations of the medical investigations maze in place, a key informant narrated thus:

> The doctor writes test, they [caregivers] collect the form, they take it to the lab, lab cost it for them … then they must go to a pay point, pay for it, then take the receipt back to the lab. Then the lab gives them a bottle, so they now bring the bottle … back to the ward, then a sample is taken; they are now, most times, handed over [to caregivers] to make it faster, because sometimes the hospital maid or the hospital assistant that is supposed to be on the ward might not be available, might need to do other things. So, they [i.e., caregivers] must take it, and take it back to the lab, and drop the sample. Then they might have to be the one to follow back, and go and pick up the result, maybe a day or two days after, and bring the result back. (DOC02, male, 30)

Depending on the clinical status of their care recipient, ICs may repeat the investigation process multiple times in one day. As one interviewee who relied on the assistance of two privately recruited helpers said, " … they can write four tests or five for someone in a day. Am I the only one that will be doing everything?" (MIC07, female, 65).

Problems can arise during the process of conducting medical tests/procedures, which further stress caregivers in performing this role. Long queue at the lab is one of such problems. At other times, ICs are told there is "no chance" to do tests, and are advised to keep checking back, as explained below:

> When they asked us to do dialysis recently, they said there is no chance, we will not be able to do it and we could not do it until the next day. We want to do echo now, since about 5 days, we have been going

> and they said there is no chance. I went there today again; they asked me to come back tomorrow again before 8 to register. If it is after 8 [AM], I should not come again, that they are fixed up. (MIC08, female, 53)

Some labs are not efficient, given that caregivers must follow-up with them closely to ensure that investigation is done. " … Sometimes I will go to one place seven times before they attend to her [i.e., her care recipient]" (MIC09, female, 63). In some cases, the inefficiencies at the labs lead to interpersonal conflict between ICs and staff of the hospital.

Additionally, some investigations require the presence of ICs as "tag along," like for ultrasound and x-ray, dialysis or theatre-related procedures. Sometimes, inpatient without a "tag along" may not be attended as IC are expected to:

> … Carry the patients for investigations; like if they must go for x-rays, when they are going to the theatre, if they have surgeries, the relatives must be on the ground; if not, the porters won't take the patient to the theatre. (DOC05, female, 36)

In the same vein, the presence of ICs is required if inpatients are non-ambulant and need a form of wheeling. Although some ICs admitted that tagging along for investigations helps to calm their sick relatives, the complications involved, the intensity and frequency of test conduct render them stressed and tired.

Finding/serving as blood donor

During the day, and while engaging in the routines, ICs may be burdened by finding blood donors. As one management staff noted, " … there are times you need them to get some things, … like you need blood donation, … the informal caregivers is the one that will connect with other people to get … " (MGMT04, female, age unknown). ICs explore connections that can lead to the identification of blood donors, including "commercial donors", even though commercial donors are not encouraged. Despite this expectation, commercialized donation is prevalent. When ICs are unable to find a donor, they are constrained to make the donation themselves.

ICs who have relatives nearby may get blood donation sorted quickly with minimal challenge. However, all our participants live far away, including from outside the state where the hospital is located. An IC mentioned how not being from the city could be a problem, observing that, "if it is not people from here that know people, finding blood donor gives someone a headache" (MIC11, female, 62).

Meanwhile, ICs sometimes fail to find blood donors for care recipients. In this situation, they play the role of blood donors because they are constrained to volunteer themselves. A caregiver who donated blood on behalf of his relative who has been on dialysis narrated that:

> When they need us to donate blood, I am the one taking care of her and donating blood. … Nothing happened to me, before I did it, I just prayed to God and God helped me. … I have not done it before because when I got to the blood bank, I asked them how many days it would take for me to recover and they said one day, and I said no problem … When I finished, I returned to continue my work [that is, his other roles]. (MIC20, male, 39)

Whether one day is adequate for post-blood donation recovery is a different issue, but it is evident that ICs who donated blood do continue with their routines immediately afterwards. The vulnerability of ICs to poor physical health is also likely heightened as they go about their already complicated routines.

"We can't find buyers for the thing we want to sell": finding money for care

Most Nigerians pay out of pocket for healthcare (Aregbeshola & Khan, 2021), and ICs become entangled in mobilizing money for patient care while stuck in the hospital and cannot work, and while lacking financial and other resources to support their prolonged stay in the hospital. Specifically, the conduct of investigations and buying of drugs, food and other consumables that hospitalized patients need demands that ICs mobilize for funds from family members and friends. "People send whatever is within their power to me, people that are my friends and church members" (MIC02, female, 37), observed one caregiver. Corroborating, an inpatient said, " … they are the ones that know how I am eating, they are the ones that know how I am doing everything, they are the ones that know how they get money" (HP06, male, 19).

Reaching beyond themselves and the hospital to find money is a burdensome necessity for ICs. One IC said, "if I beg from someone and they give me and if they don't, we will still pray" (MIC09, female, 63). But, a "sit-down-look" disposition is impossible for many ICs as money pressure makes them desperate. For example, while in the hospital, ICs look for money to offset medical bills and procure necessary drugs by collecting loans, putting up their properties for sale or just begging in the hospital community. A 70-year-old woman with a daughter on admission for 45 days collected loans while supporting her daughter, a 34-year-old woman suffering from an unresolved bone breakage following an accident that killed some people. As the participant narrated:

> Since we did not have money, I had to look for money everywhere and all over. I collected a loan. I have not finished paying so I started looking for another means that I asked for another loan. …

> They even said they would not grant the loan; may God not make us cry; all manner of things. I begged them anyway. That's what I'm dealing with. We will use it [loan] for what we want to do. (MIC15, female, 72)

For another 50-years-old woman that was caring for her 67-year-old husband who had spent 31 days, getting money is paramount. This is because, as often happens in large public hospital, they could not leave due to their inability to pay for received treatment. Even though her husband has been discharged to leave, he remains on "admission" until the hospital bill is paid. Because of their "detention admission," they have become more indebted. The cost of hospital bed never stopped, along with other expense attached to hospitalization. By his continued stay, the surgical site was infected. They were told more money would be needed for a test to know what went wrong. So, raising money was on her mind all the time. More so, their social network is overstretched which has forced them to consider selling their house, as she lamented "We are trying. We can't find buyers for the thing we want to sell. And everyone is tired" (MIC04, female, 50).

Also, to find money, desperation sets in for some caregivers who lacked resources and are far from home. A 22-year-old female caregiver reported being constrained to beg for money:

> … I was begging all about because we could not get money. The doctors are trying; they contributed money for us to pay for the test. We bought medicine and other things. (MIC05, female, 22)

She is from a single parent household, and a hairdresser earning ₦5,000 per month. Along with her mother, she has been supporting the care of her 19-year-old brother for 91 days due to a post-operative complication causing a leakage of faecal material from the side of his stomach.

Shadow caring and advocacy

The ICs advocate on behalf of the hospitalized and engage healthcare workers to improve the treatment of inpatients. There were cases when ICs confronted the nurses to attend to their care recipient on time, and to improve services to the sick. When the number of functioning dialysis machines had reduced from six to between two and three, and the waiting became frustrating, an elderly IC and her son complained and threatened to discharge their relative. As reported:

> … Four days they did not have light [i.e., electricity] and water and my son said he would carry my husband to a private hospital; it was the consultant that was telling him not to carry him … (MIC07, female, 65)

At other times, ICs watch health workers while they work, and pick on errors that could have had a negative impact on inpatients. In doing this, ICs pay attention to the operation of the wards, especially as it relates to the treatment of their hospitalized relatives. For example:

> … Maybe they are giving him IV fluid, and it finishes, or they are supposed to give him an injection and they do not know what time they should do it; when they delay, and promise to come and did not … We scream on them because we are not comfortable with it … (MIC10, female, 25)

In some other situations, ICs have acquired and shared information that averted adverse outcomes for hospitalized relative. An instance involved a 62-year-old woman and retiree who reported that her daughter almost missed an injection that would have proved catastrophic if she did not raise an alarm to point out the "negligence" (MIC11, female, 62). The doctor in-charge had requested for an injection but forgot to administer it after her daughter's blood transfusion. A nurse came by to check her file but only exclaimed "…this one has not even taken the injection … " (MIC 11, female, 62 years). Unaware of what was happening, another patient called her to ask if her daughter was given the said injection, to which she replied in the negative. This patient told her to act fast because missing the injection post-blood transfusion could push her daughter into a comatose state. From that experience, she always monitored her daughter and complained to the medical staff on her behalf.

Washing, spreading cloths, and waiting

Most of the ICs finish washing chores before daybreak, especially cloths and bedspreads. Washing of cloths near the hospital area during the day is prohibited but some ICs try to wash during the day if they can find water. After washing, some keep them in a plastic bag for drying in the sun after. However, they must monitor the clothes as they dry them in the sun. This is necessary because security guards and other staff have been directed to keep the environment clean, a task that involved removing anything that infringes the hospital's aesthetics.

Specifically, security guards are under instructions to remove, and throwaway cloths spread for sun drying in unapproved places. Spreading of cloth on railings, on low fences, around generator diesel tank or on grasses around the wards are particularly prohibited. The "approved area" for sun drying cloths changes frequently and ICs who are not familiar with the hospital could lose their few clothing to removal and seizure carried out by security guards. Like the

hospitalized patient quoted below said of her mother who was caring for her:

> … If she wants to help me wash cloth … she will have to sit with the cloth where she spreads it. … So, they will not take it … …When we arrived for the first time we did not know anywhere, we lost a lot of clothes. (HP08, female, 34)

At the time of our fieldwork, ICs were permitted to spread their clothes in a desolate area with little human traffic. Some of them complained that the space did not have where to hang clothes and looked like a waste disposal area. Ants inhabit the place, and it is common to spend time removing ants before taking the cloths to the ward for use by the inpatient.

Finally, despite the hyperactivity characterizing experiences of role routines, caregivers have breaks, periods when they sit and wait. Having breaks, however, does not make them passive as they remain relatively active in their waiting. This is because waiting must be done close to the wards, spaces they wait at to be close by—and on standby—and available to be called whenever. This means also that they must be at alert and anticipate being called upon at any time. As such, waiting must be done in a manner that normalizes their presence to perform roles expected of them within hospitalization care context.

Intersection of self-care routines: living one's life in/around hospital

As the day rolls by, ICs feed themselves along the day, while seated on iron benches near the wards, on the move or at canteens inside the hospital premises. "We go to the canteen to buy, … I will eat there, then bring his [inpatient's] own" (MIC14, female, 65). They also try to pray as part of their morning routine, but mostly not in an organized way. Praying happens spontaneously and continues throughout the day. "When we sit outside, I pray in my mind." (MIC16, female, 18). Another said, "I can't go to the church yesterday, no problem, anywhere you are, you communicate with God, so I've prayed this morning" (MIC14, female, 65).

A more spontaneous approach was adopted by an IC who once approached a group of four adult men one morning and pleaded with them, that:

> … Sir, help me to pray for my husband not to die, he is where they are treating those that have kidney problem and they asked me what his name is? And I wrote it for them … (MIC07, female, 65)

Similarly, a Muslim woman reported praying right from her hostel. She described herself as "praying for those alive, pray for the dead, for the sick and for those who are well." (MIC12-IDI-180123). Some pray for nurses and doctors too so that complications do not arise.

Nonetheless, throughout the day, access to public toilets is limited and conflicts often occur in a bid to keep up good hygiene. During the daytime, restrooms can be under lock due to water supply issues, and ICs may refuse to flush the restrooms when water is not available. Similarly, when few restrooms are available for use and are being cleaned, conflicts can ensue.

At night, between 8 PM and 9 PM, nurses and security guards request that ICs leave the wards, although some do not leave the ward until 10 PM or 11 PM. " … When someone now does that [task] from morning till night, 9 at night, that they chase us out, that someone will not find a place to sleep" (MIC07, female, 65). Whatever the time of exit, departure from the ward is like a lock-out for most ICs. This is because, although some leave for rented hostels, many ICs, especially those who came from far away, retire to the iron benches, pavements, and floors where they sit or sleep. Once retired to a potential sleeping spot, some think about their situation briefly, like an IC who said, "when I am done with all I need to do, I will just think about my office … " (MIC20, male, 39).

To sleep after leaving the ward is not without a challenge. Indeed, some reported trouble sleeping, staying up until 12 AM or longer. Sleeping at night has a disruptive rhythm. At the emergency area, for example, a participant said:

> We sit here sometimes tightly close to one another to sleep. When noise starts there, we wake up, sit up and start to look until morning; we'll not be able to sleep. They might go silent for a while that we try to sleep again, with mosquitoes hovering, that another emergency will come in [makes a sound to mimic the dragging of the trolley on the ground] that someone had died … . We will sit up wondering what had happened. (MIC15, female, 72)

There is also the reality of short sleep time. It is common for caregivers to wake up early, from 3 AM or 4 AM. This sleep time is sometimes affected by the routine of health assistants in charge of cleaning the corridors of the hospital where many ICs sleep on the floor. For many ICs, their hospitalized relatives are not aware of where they sleep and under what condition. ICs actively/consciously refrain from letting hospitalized relatives know where/how they sleep to protect them from bad feelings and regrets.

Discussion

So far, we have presented an in-depth description and analysed the role-routines of HIC as experienced by relatives of hospitalized patients in a Nigerian public tertiary health facility. Among other findings, ICs' role and their experiences of the associated tasks were shown to be complex and complicated, and often physically demanding and stressful. The complication observed in the situations narrated by participants was conditioned by the need to provide supportive

care to sick relatives while emplaced in the health facility. From very early in the morning until the night, ICs provide care under de-humanizing conditions, from bathing in the dark or sneaking to patients' bathrooms, to caring for inpatients, navigating medical investigation maze, looking for and or serving as blood donors, finding money and so on. The supportive role of ICs in term of *àdúròtì* is rooted in the Yoruba philosophy of care, which finds expression in sociological perspectives of *ajobi* and *ajogbe* (Akiwowo, 1999; also see; Omobowale & Akanle, 2017).

The roles of ICs in hospitalization are significantly germane, and health professionals informally recognize them given the degree of normalization of the roles (Sabo et al., 2022). However, the range of roles observed and extent of associated tasks and stress involved have negative implications on the physical, social, mental and spiritual well-being and health of ICs. They experienced stress from the role-routines of HIC, and were exposed to physical health risks and infections during personal hygiene maintenance, while supporting inpatient care, during routine errands and when they sleep rough in open spaces around the hospital. Adejoh et al. (2021) had earlier argued in this wise, that in Nigerian tertiary health institutions, the multi-faceted function of ICs occurs at the detriments of their own social, financial and health wellbeing. Conversely, inpatients and healthcare workers were equally at risk when ICs use toilet facilities reserved for patients or just by having contact with already vulnerable patients (e.g., drawing poo from a patient's anus). There is a need for critical engagement with how the systems dysfunction-sustained presence of ICs may be re-constituting public health facilities in low-resourced settings into an arena of ill-health production.

Also, through the role-routines, an "errand loop" is created, in which ICs are constrained to keep active, effective, and efficient for the overall care of hospitalized relatives. This errand loop greased the operation and functioning of the health facility, such that certain patient care processes, like x-rays or surgeries, may be truncated when ICs are not on the ground. Moreover, ICs' recruitment of paid carers or their practice of inviting other ICs to assist them in moving their sick relatives suggests that there is hierarchy and power in the social relation of errand loop. This is especially the case as ICs' labour is largely demanded, called, recalled, and deployed by formal health workers with little resistance.

Expectedly, women, especially the aged ones, are most burdened, thus revealing a situation of gender and age mediated lived experiences of role-routines in HIC. Gender is an important demographic data, which can influence IC outcomes, roles, extent of burden, and even coping strategies (Legese et al., 2020). Gender effect is a recurrent issue in caregiving discourses across cultures, illness episodes, and scopes which then constitutes women as mostly involved informal caregivers (Cohen et al., 2021). In Nigeria, 82.1% of women are in informal sector (Adenuga, 2021), partly accounting for the preponderance of women as ICs of hospitalized patients. While this research corroborates previous studies in Sub-Saharan Africa on the role of women in informal caregiving (Gambe et al., 2023), it further ascertains that gender would remain relevant in future projections regarding the availability of women for care-related responsibilities. Also, many of our study participants are aged and their presence points to phenomenon of hospital-based aged informal caregivers. This reality is a departure from the literature where the aged in Nigerian hospital setting have largely been located as recipients of informal caring (Gureje et al., 2006; Odii et al., 2022; Uwakwe et al., 2009). But as expected in the cultural expression of *àdúròtì*, old people are compelled to take on caregiving roles even at the detriment of their health. Hence, the involvement of the aged in HIC calls for critical attention.

Besides, having money to manage the care of hospitalized patient is crucial, especially because many of those attending public hospitals in Nigeria pay out of pocket (Aregbeshola & Khan, 2021). Access to money to offset medical bills is important at all phases of care, including after the patient has been discharged. In fact, some of the ICs reported that their sick relatives were already discharged to go home but could not do so because they owed hospital bills. Thus, inpatient, along with their ICs, remained in the health facility longer than necessary due to temporary hospital detention. In addition, prolonged stay in the hospital heightened the need for money, triggering borrowing and selling of assets, all contributing to vicarious or direct experience of catastrophic health spending among ICs. Most studies on informal care do not estimate the cost of informal care (especially in African countries), yet, the economic cost is humongous as scholarship in the broader field of informal caregiving has started to document (Adejoh et al., 2021; Bates et al., 2021; McCaffrey et al., 2015). Future studies should explore the catastrophic impact of HIC on ICs as a distinct group that is entrapped in healthcare spending alongside inpatients that have thus far been at the centre of research.

In all, the role-routines of ICs points to the complexity and systemic challenge in the Nigerian health sector. It also crisscrossed the invisible presence of ICs in the health services of under-resourced settings, even as they have become integral to the functioning of the public health sector. The intensity as well as the repetitive nature of the roles and their characteristic stress is suggestive of what can be called the "routinization of suffering" among ICs participating in HIC.

Being far away from their normal place of residence peculiarly worsened the situation.

The study has implications for how we assess the roles and cater to the needs of ICs in LMICs. It provides evidence on the physically and economically demanding and stressful labour of caring in hospital setting as performed by relatives of the sick. The findings can serve policymakers and managers of public health facilities in planning interventions and programming aimed at providing social support to and improving the wellbeing of relatives of inpatients. Regarding wellbeing, for instance, the study shows that, while stuck in the health facility and performing routinized and strenuous tasks, some ICs still donate blood to sick relatives. Experts, researchers and policymakers should be interested in the context and practice of "voluntary" blood donation, especially how it occurs under the condition of constraints and its impact on the wellbeing of ICs. Also, in showing the age and gender dynamics in the experiences of ICs, the study highlights major inequities in HIC, with significant implications for how equity is discussed and addressed in African health systems.

Conclusion

Informal caregivers function to alleviate the impact of systemic health systems failure on their loved ones who are hospitalized in large public health facility. The article has shown that the role-routines of hospital-based informal caregiving is complex and complicated for relatives of hospitalized patients. The ICs perform many roles and the routines of each roles take place throughout the day with little limit to the extent of their involvement in caring for inpatient. These roles are not only extensive but also essential in nurturing the sick back to good health. It is therefore important for policymakers and managers of public health facilities to address the vacuum being filled by ICs, thereby alleviating the burdens placed on them by everyday role-routines.

Acknowledgments

Kudus Oluwatoyin Adebayo was supported by the Consortium for Advanced Research Training in Africa (CARTA) through the CARTA Re-entry Grant Award 2022. CARTA is jointly led by the African Population and Health Research Center and the University of the Witwatersrand and funded by the Carnegie Corporation of New York (Grant No. G-19-57145), Sida (Grant No:54100113), Uppsala Monitoring Center, Norwegian Agency for Development Cooperation (Norad), and by the Wellcome Trust [reference no. 107768/Z/15/Z] and the UK Foreign, Commonwealth & Development Office, with support from the Developing Excellence in Leadership, Training and Science in Africa (DELTAS Africa) programme. The authors appreciate the support of the LEMIC Study mentors, Sharon Fonn and Ayodele Samuel Jegede, and thank Ayokunle Olumuyiwa Omobowale for reviewing an earlier draft of the article. The statements made and views expressed are solely the responsibility of the authors.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The work was supported by the Consortium for Advanced Research Training in Africa (CARTA) .

Data availability statement

The data that support the findings of this study are available from the corresponding author, KOA, upon reasonable request.

Notes on contributors

Kudus Adebayo holds a PhD degree in Sociology of Development from the Department of Sociology, University of Ibadan, Nigeria. He is Research Fellow in the Diaspora and Transnational Studies programme, Institute of African Studies, University of Ibadan, Nigeria, and Honorary Lecturer at the School of Public Health, University of The Witwatersrand, South Africa. Previously, he was Postdoctoral Fellow at the African Centre for Migration & Society, University of The Witwatersrand, Johannesburg, South Africa, Fellow of the American Council of Learned Societies (ACLS)/African Humanities Program (AHP), Fellow of the Consortium for Advanced Research Training in Africa (CARTA), and Laureate of the Council for the Development of Social Science Research in Africa (CODESRIA). His research interests cover Africa migrations, settlement and belonging, migration health, urban transformations and knowledge production.

Mofeyisara Omobowale is holds a PhD in Cultural/Medical Anthropology and a practicing Public Health Anthropologist at the University of Ibadan, Nigeria. She is a Senior Research Fellow, Social and Behavioural Health Unit, Institute of Child Health, College of Medicine, University of Ibadan. She blends anthropological knowledge, theories and methods with public health. She a team member of Ibadan LEMIC project.

Adebayo Akinyemi is a doctoral candidate in the Department of Sociology, University of Ibadan and teaches in the Department of Sociology, Osun State University, Nigeria. He was a Fellow of the Social Science Research Council (SSRC 2018/2019) and Winner (unused), American Council of Learned Society (ACLS)/African Humanities Program Fellowship (2018). His research areas include sociology of development and social change, environmental sociology, indigenous knowledge system and sociological theories.

Rukayat Usman is a doctoral student in Public Policy in the Department of Sociology, University of Ibadan, Nigeria and a recent graduate of the MA programme in Diaspora and Transnational Studies from the Institute of African Studies, University of Ibadan, Nigeria. Her research interest is broadly on migration and displacement. She has worked in research teams on data archiving and digitisation.

Atinuke Olujinmi is a doctoral candidate in the Department of Sociology, University of Ibadan, Nigeria. She is an IFRA Research Fellow, Fellow of the Ife Institute of Advanced Studies, Member of Postgraduate Writing Hub (PGWH) and currently undergoing a 1-Year fellowship in the African Graduate Mentorship and Coaching programme by IMAGES Initiative. Her research interests are in the broad field of informal livelihoods and economy in Africa, especially the women and gender context of informal economy.

Funmilayo Omodara is a public health professional and social entrepreneur with Masters of Public Health degree in Child and Adolescent Health from the College of Medicine, University of Ibadan, Nigeria. She is the Founder of The Chosen Inspiraa Foundation for Youth and Community Development, a non-governmental organization focused on Empowering Vulnerable adolescents both in orphanage homes and on street with different digital and vocational skills. She adopts qualitative and quantitative research approaches in her work and engages in community mobilisation and engagement.

ORCID

Kudus Adebayo http://orcid.org/0000-0002-3746-4963
Mofeyisara Omobowale http://orcid.org/0000-0002-9988-500X

References

Abubakar, I., Dalglish, S. L., Angell, B., Sanuade, O., Abimbola, S., Adamu, A. L. … Onwujekwe, O. (2022). The lancet Nigeria commission: Investing in health and the future of the nation. *The Lancet*, *399*(10330), 1155–1200. https://doi.org/10.1016/S0140-6736(21)02488-0

Adejoh, S. O., Boele, F., Akeju, D., Dandadzi, A., Nabirye, E., Namisango, E., Namukwaya E, Ebenso B, Nkhoma K, & Allsop, M. J. (2021). The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: A multi-country qualitative study. *Palliative Medicine*, *35*(3), 552–562. https://doi.org/10.1177/0269216320974925

Adenuga, A. (2021). *80.4% of Nigerian employed in informal sector, says W'Bank*. *The punch*. https://punchng.com/80-4-of-nigerian-employment-in-informal-sector-says-wbank/

Agbenyefia, G. (2017). *The interface between the health professionals and lay caregivers at the Koforidua Central Hospital in the Eastern Region of Ghana*. University of Ghana.

Ahmad, J. I. (2023). The imperative of medical entrepreneurship in addressing physicians' brain drain and health system strengthening in Nigeria. *Economic and Policy Review*, *21*(1), 19–27.

Akiwowo, A. (1999). Indigenous sociologies: Extending the scope of the argument. *International Sociology*, *14*(2), 115–138. https://doi.org/10.1177/0268580999014002001

Akosile, C. O., Banjo, T. O., Okoye, E. C., Ibikunle, P. O., & Odole, A. C. (2018). Informal caregiving burden and perceived social support in an acute stroke care facility. *Health and Quality of Life Outcomes*, *16*(1), 1–7. https://doi.org/10.1186/s12955-018-0885-z

Alkali, I. A. (2015). *Familial Caregiving Architectural Provision in Nigerian Hospital Wards*. Universiti Teknologi Malaysia.

Alkali, I. A. (2019). Integrating patient families' needs and preferences in Nigerian In-patient setting: An experts opinion. *African Journal of Earth and Environmental Sciences*, *1*(2), 323–330. https://ajees-assets.s3.us-east-2.amazonaws.com/media/media/17._AJEES_ID042_Integrating_Patient_Families_Needs.pdf

Alshahrani, S. H. Z. (2016). The involvement of relatives in the care of patients in medical settings in Australia and Saudi Arabia: An ethnographic study.

Amoah, P. A., Koduah, A. O., & Gyasi, R. M. (2018). "Who'll do all these if I'm not around?": Bonding social capital and health and well-being of inpatients. *International Journal of Qualitative Studies on Health and Well-Being*, *13*(1), 1435108. https://doi.org/10.1080/17482631.2018.1435108

Angood, P., Dingman, J., Foley, M. E., Ford, D., Martins, B., O'Regan, P., Salamendra A, Sheridan S, & Denham, C. R. (2010). Patient and family involvement in contemporary health care. *Journal of Patient Safety*, *6*(1), 38–42. https://doi.org/10.1097/PTS.0b013e3181d56ce6

Aregbeshola, B. S., & Khan, S. M. (2021). Out-of-pocket health-care spending and its determinants among households in Nigeria: A national study. *Journal of Public Health*, *29*(4), 931–942. https://doi.org/10.1007/s10389-020-01199-x

Asuquo, E. F., & Akpan-Idiok, P. A. (2020). The exceptional role of women as primary caregivers for people living with HIV/AIDS in Nigeria. In M. Cascella & M. J. Stones (Eds.), *West Africa suggestions for addressing clinical and non-clinical issues in palliative* (pp. 1–21). Intechopen.

Bates, M. J., Gordon, M. R., Gordon, S. B., Tomeny, E. M., Muula, A. S., Davies, H., Morris C, Manthalu G, Namisango E., & Masamba, L. (2021). Palliative care and catastrophic costs in Malawi after a diagnosis of advanced cancer: A prospective cohort study. *The Lancet Global Health*, *9*(12), e1750–e1757. https://doi.org/10.1016/S2214-109X(21)00408-3

Bei, E., Zarzycki, M., Morrison, V., & Vilchinsky, N. (2021). Motivations and willingness to provide care from a geographical distance, and the impact of distance care on caregivers' mental and physical health: A mixed-method systematic review protocol. *BMJ Open*, *11*(7), e045660. https://doi.org/10.1136/bmjopen-2020-045660

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Chukwu, N., Agwu, P., Ajibo, H., & Aronu, N. (2022). Challenges faced by informal caregivers of patients in a Nigerian hospital and implications for social work. *Journal of Social Work*, *22*(5), 1189–1206. https://doi.org/10.1177/14680173221077371

Cohen, S. A., Kunicki, Z. J., Drohan, M. M., & Greaney, M. L. (2021). Exploring changes in caregiver burden and caregiving intensity due to COVID-19. *Gerontology and Geriatric Medicine*, *7*, 2333721421999279. https://doi.org/10.1177/2333721421999279

De Silva, B. S. S. (2020). *Bystanders' perspectives on the provision of informal, hospital-based care to bedridden patients with cancer in Sri Lanka*. The University of New Mexico.

Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Feldman, P. H., Levine, C., & Gould, D. (2002). Challenged to care: Informal caregivers in a changing health system. *Health Affairs*, *21*(4), 222–231. https://doi.org/10.1377/hlthaff.21.4.222

Gambe, R. G., Clark, J., Meddick-Dyson, S. A., Ukoha-Kalu, B. O., Nyaaba, G. N., Murtagh, F. E., & Singh, R. (2023). The roles and experiences of informal carers providing care to people with advanced cancer in Africa—A systematic review and critical interpretive analysis. *PLOS Global Public Health*, *3*(4), e0001785. https://doi.org/10.1371/journal.pgph.0001785

Gureje, O., Ogunniyi, A., Kola, L., & Afolabi, E. (2006). Functional disability in elderly Nigerians: Results from

the ibadan study of aging. *Journal of the American Geriatrics Society*, *54*(11), 1784–1789. https://doi.org/10.1111/j.1532-5415.2006.00944.x

Hilton, J., Mudzi, W., Ntsiea, V., & Olorunju, S. (2013). Caregiver strain and quality of life 6-36 months post stroke. *South African Journal of Physiotherapy*, *69*(4), 66–72. https://doi.org/10.4102/sajp.v69i4.382

Hoffman, M., Mofolo, I., Salima, C., Hoffman, I., Zadrozny, S., Martinson, F., & Van Der Horst, C. (2012). Utilization of family members to provide hospital care in Malawi: The role of hospital guardians. *Malawi Medical Journal*, *24*(4), 74–78.

Hogan, U., Bingley, A., Morbey, H., & Walshe, C. (2022). The experience of informal caregivers in providing patient care in hospitals in low-and middle-income countries: A qualitative meta-synthesis. *Journal of Health Services Research & Policy*, *27*(4), 321–329. https://doi.org/10.1177/13558196221101968

Khosravan, S., Mazlom, B., Abdollahzade, N., Jamali, Z., & Mansoorian, M. R. (2014). Family participation in the nursing care of the hospitalized patients. *Iranian Red Crescent Medical Journal*, *16*(1). https://doi.org/10.5812/ircmj.12868

Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E., & Bajenja, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International*, *28*(10), 856–871. https://doi.org/10.1080/07399330701615275

Komuhangi, A., Jenkins, C., Nakaggwa, F., Agaba, P., Githinji, F., Ewuzie, A., Apio J., Namwanje A. K., & MacDonald, M. (2022). The needs, challenges, and burden experienced by informal caregivers in Uganda: A scoping review. *Discover Social Science and Health*, *2*(1), 1. https://doi.org/10.1007/s44155-022-00004-2

Legese, H., Endalew, A., Tibebu, K., & Mossie, D. (2020). The economic cost and burden of informal caregiving for the inpatient: The case of Lemlem Karl Hospital, Maichew, Ethiopia. *International Journal of Economy, Energy and Environment*, *5*(2), 14–23. https://doi.org/10.11648/j.ijeee.20200502.11

McCaffrey, N., Cassel, J. B., & Coast, J. (2015). Bringing the economic cost of informal caregiving into focus. *Palliative Medicine*, *29*(10), 866–867. SAGE Publications Sage UK: London, England. https://doi.org/10.1177/0269216315612653

Muliira, J. K., Kizza, I. B., & Nakitende, G. (2019). Roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients: Perspective from a low-income country. *Cancer Nursing*, *42*(3), 208–217. https://doi.org/10.1097/NCC.0000000000000591

Muoghalu, C. O., & Jegede, S. A. (2010). The role of cultural practices and the family in the care for people living with HIV/AIDS among the Igbo of Anambra State, Nigeria. *Social Work in Health Care*, *49*(10), 981–1006. https://doi.org/10.1080/00981389.2010.518885

Nkuranyabahizi, M., Rajeswaran, L., Ngendahayo, F., Umuhire, L., Shyaka, J. C., Dushimiyimana, V., & Chironda, G. (2021). Caring experiences and support needs among family caregivers of patients with end stage renal disease (ESRD) in Rwanda: A descriptive qualitative study. *International Journal of Africa Nursing Sciences*, *15*, 100384. https://doi.org/10.1016/j.ijans.2021.100384

Odii, A., Atama, C. S., Agbawodikeizu, U. P., & Igwe, I. (2022). Aged return migrants and the challenges of reintegration in rural Nigeria: Implications for social work practice. *The International Journal of Community and Social Development*, *4*(2), 198–215. https://doi.org/10.1177/25166026221086367

Okeke, P. C., Oparah, S. K., Oboke, S. O., & Inem, V. (2020). Care burden correlates with depression among informal caregivers of stroke patients: A cross sectional study in Lagos, Nigeria. *International Journal of Caring Sciences*, *13*(2), 1402–1410.

Okoye, U. O. (2012). Family care-giving for ageing parents in Nigeria: Gender differences, cultural imperatives and the role of education. *International Journal of Education and Ageing*, *2*(2), 139–154.

Omobowale, A. O., & Akanle, O. (2017). Asuwada epistemology and globalised sociology: Challenges of the south. *Sociology*, *51*(1), 43–59. https://doi.org/10.1177/0038038516656994

Oyegbile, Y. O., & Brysiewicz, P. (2017). Family caregiver's experiences of providing care to patients with end-stage renal disease in South-West Nigeria. *Journal of Clinical Nursing*, *26*(17–18), 2624–2632. https://doi.org/10.1111/jocn.13689

Oyeleke, M. (2023). 'How many talents have to leave before we care?': Addressing the issue of brain drain and emigration in Nigeria. *Addressing the Issue of Brain Drain and Emigration in Nigeria (July, 2023)*. https://doi.org/10.2139/ssrn.4533071

Sabo, K. K., Chin, E. D., Sethares, K. A., Revell, S. M. H., & Nicholas, P. K. (2022). Knowledge, attitudes, and practices of primary healthcare providers with assessing and supporting older informal caregivers. *Geriatric Nursing*, *44*, 159–166. https://doi.org/10.1016/j.gerinurse.2022.02.004

Sadigh, M., Nawagi, F., & Sadigh, M. (2016). The economic and social impact of informal caregivers at Mulago National Referral Hospital, Kampala, Uganda. *Annals of Global Health*, *82*(5), 866–874. https://doi.org/10.1016/j.aogh.2016.06.005

Shields, L., Arabiat, D., Ben-Sefer, E., Carter, B., Coyne, I., Foster, M., Kalembo F, & Zgambo, M. (2018). International commentary on Phiri et al. 'Registered nurses' experiences pertaining to family involvement in the care of hospitalised children at a tertiary government hospital in Malawi'. *Nordic Journal of Nursing Research*, *38*(4), 227–231.

Stavrianou, A., Kafkia, T., Mantoudi, A., Minasidou, E., Konstantinidou, A., Sapountzi-Krepia, D., & Dimitriadou, A. (2018). Informal caregivers in Greek hospitals: A unique phenomenon of a health system in financial crisis. *Materia Socio-Medica*, *30*(2), 147. https://doi.org/10.5455/msm.2018.30.147-152

Uwakwe, R., Ibeh, C. C., Modebe, A. I., Bo, E., Ezeama, N., Njelita, I., Ferri, C.P., & Prince, M. J. (2009). The epidemiology of dependence in older people in Nigeria: Prevalence, determinants, informal care, and health service utilization. A 10/66 dementia research group cross-sectional survey. *Journal of the American Geriatrics Society*, *57*(9), 1620–1627. https://doi.org/10.1111/j.1532-5415.2009.02397.x

Vincent-Onabajo, G., Ali, A., & Hamzat, T. (2013). Quality of life of Nigerian informal caregivers of community-dwelling stroke survivors. *Scandinavian Journal of Caring Sciences*, *27*(4), 977–982. https://doi.org/10.1111/scs.12017

von Kaeppler, E. P., Kramer, E. J., Donnelley, C. A., Wu, H.-H., Marseille, E., Eliezer, E., Roberts H. J., Shearer D., & Morshed, S. (2021). The initial economic burden of femur fractures on informal caregivers in Dar es Salaam, Tanzania. *Malawi Medical Journal*, *33*(2), 135–139. https://doi.org/10.4314/mmj.v33i2.9

Yakubu, K., Blacklock, C., Adebayo, K. O., Peiris, D., Joshi, R., & Mondal, S. (2023). Social networks and skilled health worker migration in Nigeria: An ego network analysis. *The International Journal of Health Planning and Management*, *38*(2), 457–472. https://doi.org/10.1002/hpm.3595

Yakubu, K., Shanthosh, J., Adebayo, K. O., Peiris, D., Joshi, R., & Robinson, J. (2023). Scope of health worker migration governance and its impact on emigration intentions among skilled health workers in Nigeria. *PLOS Global Public Health*, *3*(1), e0000717. https://doi.org/10.1371/journal.pgph.0000717

Yiu, H. C., Zang, Y., Chew, J. H. S., & Chau, J. P. C. (2021). The influence of confucianism on the perceptions and process of caring among family caregivers of persons with dementia: A qualitative study. *Journal of Transcultural Nursing*, *32* (2), 153–160. https://doi.org/10.1177/1043659620905891

Zarzycki, M., Morrison, V., Bei, E., & Seddon, D. (2023). Cultural and societal motivations for being informal caregivers: A qualitative systematic review and meta-synthesis. *Health Psychology Review*, *17*(2), 247–276. https://doi.org/10.1080/17437199.2022.2032259