"A Person Taking Care of the Sick is also a Sick Person": Challenges and Consequences of Hospital-Based Informal Caregiving

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Abstract

Informal caregivers support relatives in healthcare facilities globally. However, their involvement in hospitalization care while residing in and around the hospital is more prevalent in under-resourced settings. This article examined the challenges and multifaceted consequences of hospital-based informal caregiving in a Nigerian tertiary health facility. The study adopted a non-experimental exploratory research design and ethnographic and qualitative techniques were used to collect data from 75 participants, comprising 21 informal caregivers, 15 inpatients, 36 hospital staff, and 3 ad-hoc/paid caregivers. The challenges identified include: physical health effects and infection risks; livelihood and economic impact; mental health effects; inadequate access to basic services; exposure to safety risks and violence; conflict and barriers within the health system; and social impact. These challenges have negative consequences on informal caregivers, including heightening their vulnerability to poor health and burdening them economically and socially. Informal caregivers play a crucial role in under-resourced settings. Policymakers should create a supportive healthcare environment that meets their needs, ultimately improving the overall quality of care provided in tertiary health facilities.

Keywords

health systems, hospital-based caregiving, hospitalization, informal caregivers, lived experiences

Introduction

This article explored the challenges and multifaceted outcomes of hospital-based caregiving (HIC) among migrating informal caregivers (MICs) in a Nigerian tertiary health facility. The term "migrating informal caregivers" refers to individuals who temporarily leave their usual place of residence to support the care of hospitalized relatives within hospital settings. Providing unpaid care presents a significant global challenge.[1] Particularly, in sub-Saharan Africa, informal caregivers (ICs) are considered pivotal to Universal Health Coverage, providing valuable labor to health systems.[2,3] During hospitalization, they fulfill caretaker duties, by assisting with emotional balance, daily activities, medicine administration, appointments, and healthcare navigation.[4-7] They may also engage in specialized care activities, such as sample collection and monitoring vital signs.[8]

In Nigeria, health system challenges hinder the achievement of Universal Healthcare Coverage (UHC) goals, encompassing structural, infrastructural, and systemic issues.[9-11] A key problem is the shortage of healthcare workers, particularly health assistants and nursing staff.[12,13] This shortage results in a caregiving gap filled by family members and relatives.[14] However, ICs face significant burdens while having limited social and economic support in hospitals.[2,15,16] For instance, a study among acute stroke patients in Nigeria showed that more than 96% of ICs have a substantial caregiving burden.[17] A similar level (72%) of burden was observed in another study[18] in Nigeria, where ICs of cancer patients reported burdens stemming from recurrent hospitalizations, uncertainties about treatment success, prolonged and demanding caregiving, and a decline in the capabilities of the patients. Also, burdens on ICs of elderly hip fractures patients in a Nigerian orthopedic hospital arose from systemic factors, patient-related issues, and social and financial barriers.[19] While some studies indicate that ICs may not regret providing care, others highlight the financial costs, stress burden, and impact on work hours. These findings suggest caregiving involves both positive and challenging aspects, reflecting the complexity of the role.[18,19] Furthermore, numerous studies

highlight the associations between demographic characteristics and the experiences of ICs. ICs are predominantly female, a trend tied to traditional gender roles.[6,16] Also, while younger ICs, especially those aged 18 to 25, may have more physical strength and fewer social and health burdens, they form a substantial part of the economically active workforce. Their caregiving responsibilities can lead to significant economic losses at both household and national levels.

Findings from these studies are noteworthy, given the prevailing cultural and normative expectations that place the responsibility of caring for family members during times of need on close relatives, viewing it as a facet of social capital.[20-22] However, the phenomenon of traveling away from home to provide HIC has not received sufficient attention, especially regarding the difficulties ICs face and their consequences. In this study, therefore, we explored the everyday challenges and consequences of hospitalization-induced caregiving among MICs in a Nigerian tertiary public health facility.

This study is important to understanding the critical role of ICs in the healthcare system, especially given Nigeria's shortage of healthcare workers. It provides insights into the complex burdens that ICs staying within the health facility bear, and their vulnerabilities, which can inform policies to support and alleviate their challenges. Also, recognizing the unique difficulties faced by MICs who must leave their homes to provide care can lead to more inclusive healthcare practices and infrastructure improvements. Overall, this article can contributes to developing targeted interventions that enhance the well-being of ICs and improve the overall effectiveness of Nigeria's healthcare system. The next section outlines the methodology employed for the research, followed by the presentation of findings. A critical discussion of these findings ensues, leading to policy implications, limitations of the study and conclusion.

Methods

Research Team and Reflexivity

The fieldwork was conducted by a research team consisting of 2 university-based and experienced researchers with PhD degree in Sociology (KOA) and Medical Anthropology (MOO), and 3 graduate students recruited as research assistants from Sociology (AO) Public Health (FO) and African Studies (RAU). KOA and MOO jointly conducted the interviews with management staff and some of the health workers while the research assistants interviewed caregivers, hospitalized patients and some categories of hospital staff. All members of the research team are women except KOA who is the lead investigator. The team leads (KOA and MOO) possess sufficient research experience and took responsibility for the training and mentoring of the research assistants to prepare them for the fieldwork. The other co-authors, ODS and MC, collaborated with KOO and MOO to analyze and write up the findings for this manuscript following the COREQ checklist for reporting qualitative research.

Study Design

The study adopted a non-experimental exploratory research design that incorporated ethnographic and qualitative data collection approaches. Data were gathered between December 2022 and February 2023 through observation, in-depth and key informant interviews, and photovoice (not reported here). A total of 75 participants were interviewed, including 36 in-depth interviews (IDI) and 39 key informant interviews (KII). See Tables 1 and 2 for participants' sociodemographic information.

Setting

The research was conducted in a public tertiary health facility in southwest Nigeria. The southwest region has the highest concentration of tertiary health facilities, the highest level of care available in Nigeria. The selected health facility is one of the oldest and most advanced, with one of the largest concentration of trained medical professionals and operating clinical and non-clinical departments. The hospital provides an inpatient service with about 3 dozen wards and more than 1000 bed spaces, receiving more than 400 000 patients and admitting over 150 000 inpatients yearly as reported in 2024. While being one of the biggest in the country, the selected hospital is similar to many tertiary-level hospitals in Nigeria in most ways, especially with regards to the presence of ICs. For example, there is usually at least 1 family member to every 1 hospitalized patient who provide care assistance, even though there is limited services and amenities to cater to their needs.[16,23]

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Table 1. Socio-demographic Information: Informal Caregivers and Hospitalized Patients.

		Informal caregivers (N = 21)		Hospitalized patient (N = 15)	
Variable	Category	Frequency	Percent	Frequency	Percent
Gender	Female	15	71	9	60
	Male	6	29	6	40
Age	18-24	3	14	3	20
	25-34	2	10	3	20
	35-44	6	29	4	27
	45-54	3	14	2	13
	55-64	4	19	1	7
	65+	3	14	2	13
Education	Primary	2	10	3	20
	Secondary	9	43	3	20
	Tertiary	8	38	8	53
	Not provided	2	10	1	7
Ethnicity	Yoruba	16	76	12	80
	Others	5	24	3	20
Marital status	Single	4	19	4	27
	Married	16	76	11	73
	Not provided	1	5	-	-
Religion	Islam	6	29	3	20
	Christianity	14	67	12	80
	Not provided	1	5	-	-
	Total				
Family type	Nuclear	14	67	14	93
	Extended	5	24	1	7
	Single parent	1	5	-	-
	Not provided	1	5	-	-
Occupation	Informally employed	14	67	4	27
	Formally employed	1	5	6	40
	Student	1	5	2	13
	Retiree	4	19	1	7
	Others	1	5	-	-
	Unemployed	-	-	2	13
Monthly income	5000-10000	3	14	1	7
	10001-20000	2	10	0	0
	20001-50000	3	14	4	27
	50001-100000	3	14	1	7
	100001-150000	3	14	2	13
	150000+	1	5	-	-
	Not provided	6	29	7	47
Patient/caregiver gender	Female	10	48	11	73
	Male	11	52	4	27
Patient/caregiver age	Below 18	1	5	-	-
	18-24	3	14	2	13
	25-34	3	14	3	20
	35-44	4	19	1	7
	45-54	3	14	3	20
	55-64	3	14	2	13
	65+	4	19	3	20
	Not provided	-	-	1	7
Caregiver-patient relationship	Parent	10	48	3	20
	Spouse	4	19	7	47
	Sibling	5	24	2	13
	Children	-	-	1	7
	Other relatives	2	10	1	7
	Co-worker			1	7

(continued)

Table 1. (continued)

Variable	Category	Informal caregivers (N = 21)		Hospitalized patient (N = 15)	
		Frequency	Percent	Frequency	Percent
Place of residence	In-state	8	38	2	13
	Out-state	13	62	13	87
Duration of stay (weeks)	Less than 1	3	14	4	27
	1-2	8	38	3	20
	3-4	5	24	4	27
	5+	5	24	4	27
Ward	Medicine	5	24	1	7
	Medicine (oncology)	-	-	1	7
	Medicine (urology, diabetes)	3	14		
	Obstetrics and gynecology	3	14	3	20
	Orthopedic	1	5	-	-
	Pediatrics	1	5	-	-
	Surgery	4	19	4	27
	Surgery (oncology)	4	19	4	27
	Surgery (orthopedic)	-	-	2	13
Paired interviews	No	12	57	6	40
	Yes	9	43	9	60

Data Collection

Data collection happened during the day, at working hours, apart from our ethnographic observation which also went on overnight. This raised some challenges known with collecting data in a work setting, especially at one of the busiest health facilities in Nigeria. For example, collecting data during work hours was disruptive as interviewees sometimes requested for pauses to attend to certain issues. Some shifted appointments several times. The research team adjusted as necessary over the course of the fieldwork. Four potential IDI participants, that is ICs, could not participate in the research because of the demands of care on their time in the hospital. However, the challenges did not significantly affect our ability to have rich and in-depth conversations with all the participants.

Data collection activities occurred in the "hospital community." The community comprised wards, offices, public spaces, corridors, restaurants, restrooms and other sites within and near the hospital where the research took place—for example, four varied-styled hospital-owned hostels accommodating caregivers. We interviewed management cadre staff and doctors in their offices, while nurses were interviewed in their wards. Security guards and health assistants granted interviews at their duty posts as they could not make out a separate time. The research assistants, however, interviewed informal caregivers and ad-hoc/paid caregivers near the wards or corridors where their patients were receiving care. Although these spaces had other people in the vicinity, mainly other caregivers waiting around because they have a patient on the ward, interviews held at comfortable distances and participants spoke freely.

We documented the background information of ICs and discussed issues related to their motivations, the health situation/diagnosis of their care recipients, health-seeking related mobilities/migration, experiences of hospitalization and relationship with hospital staff and co-caregivers. Inpatients were asked to tell us about the situation of the ICs supporting them in the hospital, including sharing the extent of their familiarity with what these caregivers go through, the roles they play, and their perception of how hospital staff treat caregivers. Furthermore, we interviewed management staff, nurses, doctors, security guards, health assistants, and care worker, who, either by professional responsibility, job roles or affiliation, relate with caregivers. We asked how they perceive and relate with ICs during patient care, their contributions, the challenges and so on. Interviews with the various categories of research participants stopped after data saturation was achieved.

See Tables 1 and 2 information of all participants interviewed for the study. Socio-demographically, the ICs were predominantly females (71%), with the majority being aged 35 to 44 (29%), followed by those aged 55 to 64 (19%). The inpatients interviewed were largely females (60%), with those 44 years and below accounting for 67% of the total. The key informants too were largely females (60%) but the majority were aged 35 and above with high educational and professional achievement.

For more details on other aspects of the study's methodology details, see Adebayo et al[24] where we reported on the roles and role-routines of informal caregivers supporting hospitalized patients, especially documenting what their 24-h day is typically like in the hospital—as different from examining the challenges and consequences of HIC on them.

Table 2. Socio-demographic Information: Key Informants.

Variable	Category	Frequency (N = 36)	Percent (100%)
Gender	Female	27	60%
	Male	9	4
Age	18-24	1	3
	25-34	6	17
	35-44	14	39
	45-54	10	28
	55-64	4	11
	Not provided	1	3
Education	Secondary	6	17
	Tertiary	18	50
	Fellowship	6	17
	Masters	5	14
	PhD	1	3
Ethnicity	Edo	1	3
	Igbo	6	17
	Isoko	1	3
	Yoruba	27	75
	Not provided	1	3
Marital status	Single	5	14
	Married	30	83
	Divorced	1	3
Religion	Islam	5	14
	Christianity	30	83
	Not provided	1	3
Hospital staff category	Health assistant (environment)	5	14
	Health assistant (ward)	5	14
	Doctor	5	14
	Management	6	17
	Nurse	10	28
	Security	5	14
Ward/unit	Medicine	3	8
	Medicine (urology)	2	6
	Obstetrics and gynecology	1	3
	Orthopedic trauma	1	3
	Pediatrics	2	6
	Surgery	4	11
	Surgery (oncology)	2	6
	Surgery (orthopedic)	2	6
	Psychiatry	4	11
	Others[a]	15	42

[a]Other ward/unit of the hospital that key informants were drawn from included ENT, physiotherapy, private ward, special obstetrics and neonate sections. The staff interviewed also included those attached to key units of the hospital, such as social work, security, and other strategic departments.

Data analysis. Notes from observations and interview transcripts were transcribed in the original language of conversation and back translated to English as applicable. Transcripts were imported into the NVivo software. The thematic analysis was conducted, following the procedure outlined by Braun and Clarke.[25] We prepared a preliminary coding structure using the deductive approach. New codes were created as needed through an inductive process. Direct and summaries of quotations from the participants were extracted and presented in the findings.

An institutional ethics board reviewed and approved the study (UI/EC/22/0317), and we obtained additional official permissions from the hospital management and nursing directorate of the health facility. All participants provided written and verbal informed consents before they were interviewed.

Findings

Thematic analysis of the data unveiled seven overarching challenges. The identified themes include: (1) physical health effects and infection risks; (2) livelihood and economic impact of caregiving on caregivers and their households; (3) mental health effects; (4) inadequate access to basic services; (5) exposure to safety risks and violence; (6) conflicts and barriers within the health system; and (7) social impact. We discuss each theme next, along with consequences of the challenges they generate.

Physical Health Effects and Infection Risks

The physical health effects and infection risks of HIC illuminate the profound toll that caregiving responsibilities exact on caregivers' physical well-being. Central to this theme is the tangible physical burden of care, the physical effects of mental health challenges, and heightened risks of exposure to infectious diseases and other illnesses within healthcare settings.

Stress and its physical manifestations. ICs faced significant stress stemming from various challenges, including managing errands, navigating payment processes, and dealing with hospital systems. Despite stress being a prevalent issue, only 1 out of 21 ICs explicitly used word "stress" to describe their experience. The disparity in verbalizing stress among ICs can be attributed to their reluctance to label assistance to relatives as "stressful," as such support is considered a labor of love.

However, inpatients and hospital staff consistently used the term "stress" to articulate the challenges of ICs. Stress resulted from tasks like climbing stairs to run errands and the strenuous process of navigating hospital. For instance, an inpatient said that stress had adverse effects on the well-being of their caregiver, that, "because of the stress, he is sick, and when one is sick, psychologically he will not be able to think straight" (IDI-31, F, 38 years). This emphasizes the interconnectedness of stress with the physical and mental health of ICs.

Moreover, the demanding nature of hospitalization care led to bodily breakdown for ICs, manifesting as fever, episodes of collapsing, or fainting, potentially leading to visits to the general outpatient clinic or even hospital admission.

A nurse emphasized this risk, stating:

> A person taking care of the sick is also a sick person… I have seen at least once or twice incidents that…the person that brought somebody for something [treatment] collapsed… I have seen incidents like that, not even once, not even twice. (KII-12, F, 38yrs).

An older adult woman, aged 72, expressed her discomfort, particularly in her knees, lamenting that:

> *If it were not for old age. . . . . .All the places they tell us to go is nothing to me; I will go and then climb the stairs. I like the exercise, but I am old now and that is why climbing the stairs is challenging (IDI-15, F, 72yrs).*

Some ICs explicitly communicated their physical challenges to their hospitalized relatives, but the majority did not. They hide their challenge because they wanted their relatives to focus on getting well.

Sleeplessness and poor feeding. The sleep health of ICs was suboptimal. Many of them resorted to sleeping outside, on hospital corridors near the wards and outdoors in the open air, while a few secured accommodations in rented hostels both within and outside the hospital premises. The established routines of health assistants affected those sleeping on the corridors while some faced disturbances due to the influx of emergency admissions. Some others lay on iron benches and a few sleep while sitting, enduring the chilly weather and mosquito bites. A doctor pointed out that:

> *. . .There is no proper service to allow for where they are going to sleep overnight, for most them, . . .some people just sleep on the corridors, find a bench or a chair to sleep. . . (KII-23, M, 30yrs)*

Furthermore, the nutritional well-being of some ICs was compromised, with many reporting that they either skipped meals or relied on sugary drinks to sustain themselves. An inpatient recounted the experience of a 54-year-old aunt who was supporting her care: "Sometimes she might not eat, sometimes she might just take only *Coke* from morning till night, she won't eat anything" (IDI-30, F, 23 years).

Risk of infection and illness or exposure to risk. Infection risk was perceived as high for ICs with implications for hospital staff and inpatients. Their mere presence and stay in the hospital, and how they use certain amenities exposed them to infection. Some management staff of the hospital recognized "hanging around" as risky, stating that

> *It is not even good for such patient relations to just be sitting down there because there can be infection. . . So, a lot of people, because of that, they have carried infection. . . (KII-5, M, 55yrs)*

Contributing to the infection and health risks was ICs' experience of sleeping rough outside and overnight while exposed to cold and mosquito bites. Indeed, doctors often intervene to help ICs that fall sick in the process of caregiving as they:

> *. . .Either refer them to the general patient department for care or give them some over the counter prescription to go and get themselves sorted. (KII-25, M, 36yrs)*

Moreover, there is no dedicated toileting amenity available to relatives staying to support inpatients, and so they use general visitors'/public toilets which are too stretched and maintained poorly. Thus, how caregivers, and others, (mis)use the toilets, urinate indiscriminately and defecate inappropriately exposed them to infection. However, infection risk was not limited to ICs. Staff working in the hospital also felt at risk of being infected with unknown diseases due to how ICs (mis) used facilities, such that, "Sometimes if we want to enter the toilet. . .we may have met blood on the floor and we will not know who ever did it. . . . .Meeting faces on the closet. . ." (KII-27, F, 43 years).

Livelihood and Economic Impact of Caregiving on ICs and Their Households

This theme highlights the economic repercussions of caregiving, showing the interplay between HIC duties and economic instability of ICs and their families. Issues such as the financial outlay for caregiving, loss of livelihoods, and debt, show the cost of caregiving beyond emotional and physical tolls.

Financial constraints. Initially, ICs faced financial constraints which hampered their functioning and capability to support the care of sick relatives. They were strained financially and unable to fully support hospitalized relative and themselves. A 60-year-old man expressed the toughness of not having money:

> *Money is not available when we need to spend. . .it is not available sometimes; it is tough for me sometimes and makes me sad and cry a lot. (IDI-6, M, 60yrs)*

The financial constraints hindered ICs' access to supplemental services, such as hiring helpers, renting accommodations, making deposits, and purchasing meal tickets. Additionally, due to these constraints, caregivers became disinterested with their role and uncooperative with health workers who frequently rely on them to care for inpatients (KII-24, F, 36 years).

Loss of livelihood and accumulation of debts. Loss of livelihood emerged as a significant casualty for ICs. While providing hospitalization care, ICs struggled to sustain their livelihood. Some of the ICs belonged in the working-age population and the time spent on caregiving was time lost for economically productive activities. A couple, in particular, reported shutting down their business because they could not cope. The wife, who came from northern part of Nigeria to the southwest region, narrated thus:

> *Since. . .my husband's health issue started disturbing him, like from last year, the ending of last year. Let me say the middle of last year, our business has been closed, so our shops are locked, nobody is running the business again. . . (IDI-19, F, 25yrs)*

Another man, a 35-year-old tricycle driver whose wife suffered postpartum hemorrhage, reported that he stopped working. While he waited on a seat around the ward for instructions from medical staff, he pointed in the direction of his parked tricycle inside the hospital. With his livelihood on hold, he had been borrowing to support the care of his wife while also spending on baby formula to feed their new-born at home. For many, debts escalated as their stay in the hospital prolonged.

Mental Health Effects

The mental health effects underscores the profound stress and anxiety stemming from caregiving challenges, compounded by the strain of livelihood and financial burdens. ICs endured the emotional toll of witnessing poor treatment and the suffering of others within healthcare facilities, thus exacerbating their distress and feelings of helplessness and emotional exhaustion.

Frustration and anxiety. ICs were mentally strained and experienced anxiety which impacted their overall health and well-being. On the corridors of wards where ICs usually congregate, it was common to hear complaints and bad comments about healthcare professionals, especially against nurses and doctors. Inside the wards, exhausted ICs expressed frustration as well. In one case, a woman in her late 60s refused to help her 70-years old husband to the restroom. Before she "snapped" on that day, she had relied on the assistance of male co-ICs nearby for assistance as nurses were not enthusiastic to help. Being an older adult herself, she was frustrated by the exhaustion and demands of care, despite having two paid ad-hoc carers assisting her. More so, negative feelings of ICs worsened when their relatives did not improve (IDI-8, F, 53 years). These mental health problems manifested as anger, paranoia, aggression toward hospital staff and even their hospitalized relatives.

Exposure to others' suffering. ICs were also exposed to the suffering of others, with impact on their wellbeing. By other's suffering, we mean not only the witnessing of the pains and discomfort of the inpatients but also seeing other ICs struggle with loss. There were also chance encounters with dying people and sickness, as one carer mentioned:

> *. . .What we have seen here is a lot. For instance, like someone dying, things I have not seen before or sicknesses I have not seen before that I met here. (IDI-17, F, 53yrs)*

Because ICs spend a lot of time with other ICs, they become familiar with each other and the condition of their respective care recipients. Thus, ". . .losing one patient while they are present too, doesn't help their psychology, so some of them can be down" (KII-26, F, 36 years).

Inadequate Access to Basic Services

Inadequate access to basic services highlights the challenges ICs encounter in accessing essential amenities crucial for their well-being and caregiving responsibilities. This theme underscores the experience and impacts of lack of adequate and safe accommodation, inadequate access to electricity, and inability to maintain hygiene standards and safeguard their health.

Navigation of overstretched healthcare facility. The healthcare facilities were difficult to navigate, particularly when amenities that should aid movement were not working optimally or located far away, for example, elevators and toilets, respectively. When ICs arrived newly especially, a doctor explained that:

> *. . .They have difficulty locating the various places that we ask them to go. For instance, the blood bank is a bit far from where the laboratories are, and the pay points are not even near (phone beeps) they need to pay. . . .So, I think the logistics in accessing care too is part of the problems. (KII-24, F, 36yrs)*

The difficulty in navigating the hospital contributes to the physical health challenges already described above. More challenging, however, is that available amenities in the facility were stretched beyond their carrying capacity. In the words of a 65-years old female carer:

> *The [hospital] did not have light [i.e. electricity] for four days and water for four days; . . .it is this my leg that I used to climb the stairs, we now carried 25 litres [keg of] water. (IDI-7, F, 65yrs)*

Also, many ICs have challenges with accommodation while supporting sick relatives. A major driver of this accommodation challenge is the fact that many ICs ". . .came from different places, different states" (KII-14, F, 45 years). Although there are hospital-owned hostels in place, access was limited and many ICs were unable to afford the rent.

Water, sanitation, and hygiene (WASH). Water, sanitation, and hygiene challenges posed significant difficulties for ICs with repercussions not only for ICs but also for the inpatients and hospital staff. ICs had limited access to water, a crucial resource needed to support the care of hospitalized relatives. The problem of water shortages was both intense and consequential, as illustrated by the case of a 65-year-old woman whose 70-year-old husband was undergoing dialysis treatment. Despite employing two paid ad-hoc carers, she expressed frustration over the unavailability of water, questioning rhetorically, ". . .do you know. . .that they don't have light for four days and water for four days?" (IDI-7, F, 65 years).

When water was available but in short supply, hospital cleaners faced challenges in maintaining hygienic amenities. Consequently, ICs struggled to uphold healthy hygiene practices, as expressed by one participant:

> *There was no place to urinate or defecate. We ended up defecating in the open, as they stated that only the person we brought is allowed to use the toilet. . . .I had to urinate on myself three times today because there was no available spot. (IDI-2, F, 37yrs)*

The situation was exacerbated by the fact that the hospital did "not provide a place for them to have their bath. . ." (KII-27, F, 43 years), forcing many to bathe in the open, in darkness, and at unusually early hours (ranging from 3 AM to 5 AM).[24]

Adding to the challenges, is that clothing hygiene was poor for many ICs and their hospitalized relatives, who often wore the same garments and used the same bedsheets for an extended period.

Exposure to Safety Risks and Violence

Being a public health facility, the hospital is perceived as an open community with in adequate entry-exit control. Therefore, ICs were vulnerable to various risks, including harassment, theft, and fraud. ICs sleeping outside faced personal safety risks, such as injuries from escaping aggressive patients. For instance, an inpatient detailed that:

> *. . .A patient ran away from the ward. . .then they started running up and down that everybody was running, the securities [staff] were running, everybody were shouting eh! eh! eh! Police even came into the compound. . . .So, it is not safe sleeping outside. . . [At] the ward, they lock the door. . . (IDI-30, F, 23yrs)*

ICs residing in hostels were not exempt from risks. In a hospital-owned hostel, we inquired about a marked-out space for a TV, and a health assistant revealed that the TV set had been stolen overnight over a year ago. Additionally, there was a lack of security guard in one hostel, particularly the cheapest sited outside the hospital premises, even though a more populated hostel behind it had a consistent guard.

Conflict and Barriers Within the Health System

This theme uncovered both interpersonal conflict with healthcare workers and barriers as they struggled with strained relationships and communication breakdowns with healthcare personnel, worsening their caregiving burdens and impeding the provision of quality care. Relational and attitudinal issues experienced include interpersonal conflict shaped by information asymmetry, misunderstanding and language barriers.

Interpersonal conflict often arose between ICs and hospital staff. ICs complained that they were not respected, with staff "addressing me in a manner that I'm not satisfied with" (IDI-20, M, 39 years) or "as if you are nothing, as if. . .what you come to do here is nonsense" (IDI-13, M, 40 years). Some perceived that they were being ignored or not appreciated by staff who may themselves have been under pressure. Thus, interaction with staff who they encounter at labs, pharmacies, and pay points often became confrontational and aggressive, as highlighted thus:

> *I've actually fought with people at cash point. Whereby you will see two people discussing [and] you come there; you want to pay, they will leave you, they will abandon you. . . And you know, they only leave you with a small window [to see them]. (IDI-21, M, 38yrs)*

Information asymmetry and misunderstanding/miscommunication differences also caused interpersonal conflict between ICs and hospital workers (mainly nurses, doctors, and management staff). ICs sometimes did not receive adequate diagnostic and prognostic information, causing them to become agitated and confrontational. At other times, they are issued incomplete instructions by inattentive health workers, thus affecting the effective functioning of ICs.

Social Impact of Hospital-Based Caregiving

The social impact of HIC highlights challenges that extend beyond the confines of the healthcare setting, affecting ICs' interactions, relationships, and support networks within their broader social environment. Some ICs felt confined and immobile in the hospital, unable to engage in their previous life routines. Their prolonged stay isolated them from their social lives at home, leading to feelings of loneliness and boredom. A woman from the Northern part of Nigeria, caring for her husband, expressed:

> *Over there in Yola you will know where to go, you have friends, you have relatives and all that. You can go out, you can go to your business area and all that, but here, you just sit around doing nothing. Just hospital things. (IDI-19, F, 24yrs)*

Meanwhile, prolonged stays in the hospital affected ICs' religious routines and commitments. For many, meeting religious obligations became unattainable, given the belief that "you worship God when you are comfortable and in good health" (IDI-4, F, 50 years). Participants shared instances of missing attendance at church services, and an Imam expressed how HIC affected his religious leadership role (IDI-12, M, 41 years).

Discussion

We have examined the challenges and consequences of hospital-based informal caregiving by focusing on the experiences

of migrating ICs supporting hospitalization care in Nigeria. As Nigeria strives for UHC, the often unacknowledged yet deeply ingrained role of ICs, along with their exposure to suffering and dehumanization while caring for the sick, sheds light on the disparity between national health objectives and the realities on the ground. By addressing a significant knowledge gap and highlighting the potential crisis of abjectivity in tertiary health facilities, this study underscores the unique challenges faced by those supporting hospitalized patients while far away from their usual places of residence.

The commonly known outcome of caring for hospitalized patients in hospitals is eventual bodily breakdown of the ICs.[20] Nearly all the ICs in our study faced adverse health effects, including stress, physical exhaustion, weakness, pain, and sleep disturbances. These issues were exacerbated by tasks such as running errands and navigating the hospital, leading to negative health outcomes. The assertion that "a person taking care of the sick is also a sick person" captured the outcome of caregiving in an under-resourced health system with limited amenities and system failure.

Moreover, cultural and familial expectations influence caregivers' preferences to support sick relatives, underscoring how cultural beliefs and social dynamics shape healthcare in Nigeria.[26,27] However, this preference exacerbate challenges for ICs, as they may lack access to necessary amenities while providing hospitalization care. Many ICs in this study have limited affordable accommodation options, leading some to sleep near hospitals due to proximity needs. The prevalence of theft, harassment, and fraud experienced by ICs while "residing" or sleeping in and around hospitals exposed the vulnerability of this population within healthcare settings. The fact that ICs accept these adverse care experiences as the norm neglects the detrimental effects on their ability to provide effective support to sick relatives. It also highlights systemic but neglected accessibility issue in Nigerian hospitalization care structure.

What is more, the World Health Organization (WHO) has emphasized that access to safe WASH is essential not only for health but also for dignity.[28] Unfortunately, the Nigerian tertiary hospital lacked adequate WASH facilities for workers, patients, and ICs. Deteriorated and overwhelmed WASH facilities lead to open defecation and the clandestine use of cleaning equipment for bathing. These practices increase infection risks for both ICs and patients, complicating treatment and adding strain on health workers.

In all, the health systems deficiencies that made ICs indispensable reflect a serious systemic problem, especially as the hospital facilities were not initially designed to accommodate ICs.[29] The "visit-then-depart" model envisioned for Nigerian tertiary health system is not aligned with contemporary reality which is defined by low funding and staff shortage.[30]

Policy Implications

Policy-makers and health systems managers must adopt whole-systems approach to addressing and mitigating the consequences of challenges facing ICs in Nigeria. Our findings highlight the urgent need for comprehensive healthcare reforms to alleviate the burdens associated with hospital-based caregiving in Nigerian tertiary health facilities. Policymakers must prioritize the enhancement of infrastructure, amenities, and services within these facilities to alleviate the burdens faced by ICs and mitigate the negative health outcomes associated for ICs. Also, measures should address systemic failures impacting ICs, such as stress and poor health outcomes, by training healthcare workers to support them. Finally, attention should be paid to assessing and measuring the impact of livelihood loss and economic lack arising from the provision of hospitalization care among family of ICs. This would assist in gauging what is lost or gained from hospital-based caregiving, and the cost of assistance required to help ICs adjust financially.

Limitations of the Study

While the study provides crucial evidence on the challenges and consequences of hospital-based informal caregiving, there are a number of limitations of worth highlighting. The data for the study was collected from one public tertiary health facility in Southwestern part of Nigeria. As such experiences drawn from there may not reflect the situation in other regions of the country, nor the condition of informal caregivers supporting relatives hospitalized in secondary-level or private health facilities. Also, even though we show the challenges faced by informal caregivers, the study could not account for how such experiences may vary by different categories of inpatients they care for. The gendered context of the experiences reported is also be very important, although the current article did not explore it in-depth. These are important gaps that future research can explore. Considering these limitations, however, it is imperative to interpret the findings of this study with caution.

Conclusion

As the role of ICs continues to expand in countries where tertiary health facilities are under-resourced, it is crucial to prioritize their support and well-being. In Nigeria especially, where the fragility of the healthcare system has led to misalignments and poor coordination, urgent action is needed to address the current deterioration that impact relatives who support hospitalization care. Such actions are vital for creating a healthcare environment that is supportive, sustainable, and responsive to the needs of all stakeholders involved, ultimately enhancing the quality of care provided within tertiary health systems.

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Author Contributions

Kudus Oluwatoyin Adebayo and Mofeyisara Omobowale contributed to the conceptualization, the study design, data collection, data analysis and drafting of the manuscript. Oluwaseyi Dolapo Somefun and Marisa Casale contributed to the data analysis and drafting of the manuscript. Rukayat Usman, Atinuke Olujimi and Funmilayo Omodara contributed to data collection. All authors reviewed and agreed on the final manuscript for submission.

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Ethical Statement

Our study was approved by the UI/UCH Ethics Committee of the College of Medicine, University of Ibadan (approval no. UI/EC/22/0317) on November 02, 2022. All participants provided written informed consent prior to enrollment in the study.

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References

1. Zarzycki M, Seddon D, Bei E, Dekel R, Morrison V. How culture shapes informal caregiver motivations: a meta-ethnographic review. *Qual Health Res*. 2022;32(10):1574-1589.
2. Adejoh SO, Boele F, Akeju D, et al. The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: a multi-country qualitative study. *Palliat Med*. 2020;35(3):552-562.
3. Legese H, Endalew A, Tibebu K, Mossie D. The Economic Cost and Burden of Informal Caregiving for the Inpatient: The Case of Lemlem Karl Hospital, Maichew, Ethiopia.
4. El Ayadi AM, Mitchell A, Nalubwama H, et al. The social, economic, emotional, and physical experiences of caregivers for women with female genital fistula in Uganda: a qualitative study. *Glob Public Health*. 2023;18(1):2242458.
5. Berry LL, Dalwadi SM, Jacobson JO. Supporting the supporters: what family caregivers need to care for a loved one with cancer. *J Oncol Pract*. 2017;13(1):35-41.
6. Muliira JK, Kizza IB, Nakitende G. Roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients: perspective from a low-income country. *Cancer Nurs*. 2019;42(3):208-217.
7. Strauss S, Kitt-Lewis EA, Amory M. "I don't feel like I have any control of my life at all . . . everything overwhelms me. Everything": analyzing caregiver uncertainty and control through stance marking. *Qual Health Res*. 2019;29(12):1794-1809.
8. Khosravan S, Mazlom B, Abdollahzade N, Jamali Z, Mansoorian MR. Family participation in the nursing care of the hospitalized patients. *Iran Red Crescent Med J*. 2014;16(1):e12686.
9. Umeh CA. Challenges toward achieving universal health coverage in Ghana, Kenya, Nigeria, and Tanzania. *Int J Health Plann Manage*. 2018;33(4):794-805.
10. Adeloye D, David RA, Olaogun AA, et al. Health workforce and governance: the crisis in Nigeria. *Hum Resour Health*. 2017;15(1):32.
11. Omoleke II, Taleat BA. Contemporary issues and challenges of health sector in Nigeria. *Res J Health Sci*. 2018;5(4):210-216.
12. Kinfu Y, Dal Poz MR, Mercer H, Evans DB. The health worker shortage in Africa: are enough physicians and nurses being trained? *Bull World Health Organ*. 2009;87(3):225-230.
13. Ahmat A, Okoroafor SC, Kazanga I, et al. The health workforce status in the WHO African region: findings of a cross-sectional study. *BMJ Glob Health*. 2022;7(Suppl 1):e008317.
14. Determeijer JJ, Leopold SJ, Spijker R, Agyemang C, van Vugt M. Family participation to enhance care and tackle health worker shortages in resource-limited hospitals: a systematic review. *J Glob Health*. 2023;13:04005.
15. Folashade W, Jordan S, Markus W, Ajayi A. Experiences of Family Care Givers of Patients with Surgical Site Infections at Jos University Teaching Hospital Nigeria. 2021.
16. Chukwu N, Agwu P, Ajibo H, Aronu N. Challenges faced by informal caregivers of patients in a Nigerian hospital and implications for social work. *J Soc Work*. 2022;22(5):1189-1206.
17. Akosile CO, Banjo TO, Okoye EC, Ibikunle PO, Odole AC. Informal caregiving burden and perceived social support in an acute stroke care facility. *Health Qual Life Outcomes*. 2018;16(1):1-7.
18. Jite IE, Adetunji AA, Folasire AM, Akinyemi JO, Bello S. Caregiver burden and associated factors amongst carers of women with advanced breast cancer attending a radiation

oncology clinic in Nigeria. *Afr J Prim Health Care Fam Med*. 2021;13(1):e1-e8.
19. Diameta E, Adandom I, Jumbo SU, Nwankwo HC, Obi PC, Kalu ME. The burden experience of formal and informal caregivers of older adults with hip fracture in Nigeria. *Sage Open Nurs*. 2018;4:2377960818785155.
20. Hogan U, Bingley A, Morbey H, Walshe C. The experience of informal caregivers in providing patient care in hospitals in low- and middle-income countries: a qualitative meta-synthesis. *J Health Serv Res Policy*. 2022;27(4):321-329.
21. Nkuranyabahizi M, Rajeswaran L, Ngendahayo F, et al. Caring experiences and support needs among family caregivers of patients with end stage renal disease (ESRD) in Rwanda: a descriptive qualitative study. *Int J Afr Nurs Sci*. 2021;15:100384.
22. Ananias J, Keating N. Experiences of family carers of older people in marginalised communities in Namibia. *Int J Care Caring*. 2023;7(2):307-325.
23. Fasiku MM, Akande OW, Bolarinwa OA, Akande TM. Prevalence and determinants of stress of informal caregiving: A cross-sectional study among informal caregivers of hospitalised patients in a tertiary hospital in Nigeria. *Niger Postgrad Med J*. 2022;29(1):20-28.
24. Adebayo K, Omobowale M, Akinyemi A, Usman R, Olujimi A, Omodara F. "I am the one taking care of her and donating blood": lived experiences of role-routines of hospital-based informal caregiving in Nigeria. *Int J Qual Stud Health Well Being*. 2024;19(1):1-13.
25. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology*. 2006;3(2): 77-101.
26. Ezulike JCD, Lu S, Chiu MYL. Aging and caring: exploring older adults' motivation for informal caregiving to other aging individuals in Nigeria. *Innov Aging*. 2024;8(4):igad140.
27. Ebimgbo SO, Atama CS, Igboeli EE, Obi-keguna CN, Odo CO. Community versus family support in caregiving of older adults: implications for social work practitioners in south-East Nigeria. *Community Work Fam*. 2022;25(2):152-173.
28. World Health Organization. *WHO Water, Sanitation and Hygiene Strategy 2018-2025*. World Health Organization; 2018.
29. Alkali I. *Familial Caregiving Architectural Provision in Nigerian Hospital Wards*. Universiti Teknologi Malaysia; 2015.
30. Ogueji IA, Ogunsola OO, Abdalla NM, Helmy M. Mistrust of the Nigerian health system and its practical implications: qualitative insights from professionals and non-professionals in the Nigerian health system. *J Public Health*. 2024;32(2):303-314.