Challenges faced by informal caregivers of patients in a Nigerian hospital and implications for social work

Ngozi Chukwu
Department of Social Work, University of Nigeria

Prince Agwu
Department of Social Work, University of Nigeria; Health Policy Research Group, College of Medicine, University of Nigeria; School of Education and Social Work, University of Dundee

Henry Ajibo
Department of Social Work, University of Nigeria

Ngozi Aronu
Department of Sociology and Anthropology, University of Nigeria

Abstract

Summary: Unlike in the global-north where care of hospital in-patients is within the remit of the nursing and social care staff, the burden of care in most Nigerian hospitals is borne by informal caregivers who are relatives, family members or friends of the in-patients. Their unpaid roles in ensuring health and wellbeing of in-patients cannot be overstated, yet they remain often invisible to and unappreciated by hospital authorities. We used in-depth interviews to glean lived experiences of 24 informal caregivers in a tertiary hospital in Nigeria. This study adopted phenomenology as its overall theoretical underpinning that guided data collection and analysis. As also recommended by phenomenology, thematic clusters were employed for analysis.

Corresponding author:
Prince Agwu, Department of Social Work, University of Nigeria, Nsukka, Nigeria; Health Policy Research Group, College of Medicine, University of Nigeria Enugu Campus, Enugu, Nigeria.
Email: prince.agwu@unn.edu.ng
Findings: The narratives of the respondents revealed that caregiving constitutes a lot of ordeals which are worsened by some unwholesome conditions in the hospital for informal caregivers who seem to be left to fend for themselves. Three overarching themes emerged from the interviews which are, challenges of informal caregivers, conditions that exacerbate the challenges, and steps to improve coping capacities.

Applications: Informal caregivers remain an essential force in the care of hospitalised patients yet are poorly attended to by healthcare authorities. There is a need to pay attention to their needs through a comprehensive health policy to accommodate them as a priority concern in the care of patients. Social workers can be meaningful in scaling up responses and response plans to that effect. Hence, the need to advance the professionalisation of social work in Nigeria deserves speedier attention.

Keywords
Health, health and social care, medical social work, managed care, carers

Introduction
Patients who are admitted to hospitals could go through discomforts in the process of recovery or management of their health, which makes caregiving an important aspect of their care. While it is acceptable that patients should be given much attention, it is worrisome that in Nigeria, family members, relatives, and friends who spend great amount of time attending to the care needs of the patients are neglected (Gabriel et al., 2019). Informal caregivers as technically described, get involved in meeting the daily needs of patients which could include bathing the patient and washing their belongings, feeding the patient, making meals, always staying by the bed of the patient to alert health workers in the event of patient’s distress, etc. (Gabriel et al., 2019; Kent et al., 2016; National Cancer Institute, 2019). Owing to such responsibilities, they are bound to face several challenges such as poor health conditions, losing their jobs, restricted social life, emotional disturbances, financial strains, risk of being infected, to mention but a few (Kaur et al., 2018; Liang et al., 2018; Sercekus et al., 2014; Yigitalp et al., 2017). Yet their conditions are barely considered within healthcare policies and administration, especially in countries within the global south. Little wonder they are referred to as ‘invisible patients’ in some studies (Adelman et al., 2014; Northouse et al., 2012).

Informal caregivers tend to be invisible not just to the healthcare system but could be invisible to even the patients they help. This is because they are bound to shield their feelings from patients to prevent exacerbating their conditions, whereby they come to know that their informal caregivers are not doing fine (Sercekus et al., 2014). Many countries in
the global south, and especially, Nigeria, barely make strategic healthcare considerations for informal caregivers as highlighted in some studies (Adelman et al., 2014; Inogbo et al., 2017; Sharma et al., 2016). This could in part, be attributed to the filial culture inherent in most African and Asian countries, where it is believed that care for the sick should be the sacrifice family members should make wholeheartedly (Hu et al., 2016; Nayak et al., 2014).

Given the difficulties faced by informal caregivers, countries in the global north are increasingly offering policy and programmatic attention to them, even though informal caregivers in those climes are barely involved in the direct care of their sick loved ones. In Canada, United States of America [USA], United Kingdom and Sweden, there are several economic and social security packages for informal caregivers, which is to enable them cope with the burden associated with being close to a loved one that is sick (Northouse et al., 2012). This is complemented by increasing research and curriculum development around making lives better for them in the global north countries, and even in China (Hu et al., 2016; Liang et al., 2018; National Cancer Institute, 2019).

Informal caregivers are indeed considerably challenged, and studies have revealed that certain factors could influence the extent of their challenges. Females and older adults bear the brunt of these challenges because they comprise the bulk of informal caregivers (Hu et al., 2016; Kaur et al., 2018; Kent et al., 2016; Liang et al., 2018; Sharma et al., 2016). Income and level of education of the informal caregivers were exceptionally mentioned as influential factors, as those who are economically weak and poorly or not educated tend to suffer more (Gabriel et al., 2019; Inogbo et al., 2017). However, some strategies to help informal caregivers exist in literature. They centre on health insurance to help the poor, adequate information about the disease to help caregivers know their fate and develop hope, health workers interacting with the informal caregivers and getting involved with their concerns, special education on coping mechanisms for the caregivers by social workers and increasing social support from their social networks (Lee et al., 2018; Ume et al., 2013).

In Nigeria, social work is still an emerging profession, and yet to gain a professional status by an act of law (Olajire, 2020; Onalu et al., 2020). Becoming a medical social worker in Nigeria is based on securing a social work job in any health facility, which is a basic criterion for registration with the Association of Medical Social Workers of Nigeria (AMSWON) (Okoye & Agwu, 2019). However, AMSWON seems challenged by the employment of non-social workers to do medical social work in Nigeria, as well as the poor recognition of the profession and its roles even among other healthcare professionals that work in healthcare facilities (Okoye, 2019; Onalu et al., 2020). This could be why tertiary healthcare service users barely get to know that there are social work services in the hospitals. Moreover, there is the conspicuous absence of AMSWON on the web page of the Hospital Services Division in Nigeria (Federal Ministry of Health, 2020), which also speaks to the poor recognition of the profession even among healthcare authorities. Given the foregoing, it is usually obtainable to find patients and caregivers who are unaware of the services of social workers in the health setting (Ogunyemi, 2015; Okoye & Agwu, 2019).
Owing to the sub-optimal conditions medical social workers find themselves in Nigeria, including the dearth of funding of the medical social work units (Ahmed et al., 2017), they barely address the psychosocial needs of the patients and their caregivers (Okafor et al., 2017). At best, they take up mild counselling roles for several patients, as well as informal caregivers by extension, and are at the forefront of helping indigent patients and caregivers to raise funds for their hospital bills (Ahmed et al., 2017). In fact, a recent study by Agwu and Okoye (2021) showed that the roles of social workers in tertiary healthcare facilities were described as “reductionary”, since medical doctors and nurses consider them as people who only help the poor to raise funds to settle their medical bills. Yet in an ideal context, social workers can do more (Adelman et al., 2014; National Cancer Institute, 2019; Yigitalp et al., 2017). They could assist informal caregivers to adapt to their new roles by transfer of certain coping skills, advocate for them at their workplaces, help them secure health insurance, secure adequate information about the illnesses of patients, aid with the discharge plans, home care and reintegration, and also link them to relevant resource systems. Unfortunately, the lack of professionalisation and funds stall the fulfilment of these roles (Igwe et al., 2019; Okoye & Agwu, 2019). Therefore, our study offers an added voice to the ongoing conversations on the professionalisation of social work in Nigeria, especially, given the enormous roles, social workers should play in healthcare. Against the backdrop, we acknowledge the paucity of Nigerian-based studies on concerns of informal caregivers in Nigerian hospitals, let alone studies that locate the importance of social workers in this respect. Our study seeks to fill this knowledge gap by providing narratives relating to the ordeals of informal caregivers, the conditions that necessitate them, and the remedial steps that could be taken.

Methods

Study area

The study was conducted in one of Nigeria’s tertiary hospitals. Nigeria has 3,534 hospitals, 950 are in the public sector. There are 54 federal tertiary hospitals in Nigeria, comprising 20 teaching hospitals, 22 federal medical centres, and 3 national orthopaedic hospitals (Eke, 2015).

Federal hospitals in Nigeria are managed by the Boards of Management of Federal Tertiary Health Institutions in Nigeria under the Hospital Services Division of the Federal Ministry of Health (Federal Ministry of Health, 2020). Thus, the structure of federal health institutions in Nigeria is homogenous, since they source power and directives from just the Federal Ministry of Health. A report by Iroanusi (2019) reveals the Nigerian Federal Legislature interrogating the country’s Minister of Health on the poor state of federal teaching hospitals across Nigeria. This suggests that the hospitals are faced with common problems, which cannot be farfetched from the fact that they are managed by a common body. The studied hospital was purposively chosen by the researchers with considerations for resources, time, and fitness with the purpose of the study.
The studied hospital has a total of 19 wards which include among others, male medical ward, female medical ward, male surgical ward, female surgical ward, psychiatric, antenatal, special care, neurology, private, and ophthalmology wards, as well as 2 intensive care units [ICUs], Children Emergency Room [CHER], Newborn Special Care Unit [NBSCU] and Accident & Emergency [A&E] Units. As at the time this study was conducted in 2019, the facility had 481 bed spaces to accommodate an average of 200 patients monthly. In terms of health personnel, the hospital has 748 Medical Doctors (excluding House Officers), 481 Nurses, and 10 Medical Social Workers.

Records from the hospital showed no documentation of informal caregivers. However, with about 200 patients each month, it is estimated that at least an equal number of patients’ support networks moved in as informal caregivers. The absence of any formal documentation of these people is a clear indication that hospital authorities do not adequately recognise them. Conversations with the staff of the facility reveal that there is no existing care policy for informal caregivers of patients. Thus, informal caregivers are left to fend for themselves and could be susceptible to a wide range of unpleasant experiences in the course of fulfilling their caregiving duties.

The healthcare professionals work with the informal caregivers to attend to patients. So, informal caregivers are always at the bedside and around the patients, staying in-between the patients and their healthcare providers. Social workers and nurses appear to be closest to the informal caregivers owing to their job descriptions that connote social care to patients. But since social workers are not as popular as nurses in the hospital setting, what is seen most often are informal caregivers relating more with nurses. This could be because of the assistive core clinical health services the nurses render to the patients, such as checking blood pressure, administering drugs and injections, monitoring infusions and patient’s recovery process, etc. Intuitively, the nurses are seen by the informal caregivers and patients as a direct influence on the recovery process, as opposed to how social workers are seen.

**Sampling procedure and data collection**

A combination of purposive and availability sampling techniques was adopted in the selection of 24 informal caregivers who were aged 18 years and above. The nurses whom we rightly presumed to relate more with patients helped us with identifying the informal caregivers from various wards and units in the hospital. The selection of 24 respondents is founded not on the representativeness of the study population, but on the need to handle data saturation (Saunders et al., 2018). We got to know we had reached data saturation when we kept having repetitive narratives continuously. At that moment, we knew it was time to stop. Besides, we needed to pay attention to not having a large amount of data beyond what we can manage, as advised in qualitative research (Crouch & McKenzie, 2006).

Purposive and availability sampling techniques were adopted given the strenuous nature of informal caregiving which makes life difficult for caregivers already. Those who consented to participate did so either in writing or verbally depending on the choice of the respondent. We discovered that some did not have the time to go
through a written document, hence verbal consent became the alternative. Both verbal and written informed consent procedures addressed issues of confidentiality, anonymity, voice recording, note-taking and respondent’s discretion to withdraw from the study at any time. Our study comprised more women than men, which could be because of the gender dynamic in informal caregiving where women dominate the system.

Data were sourced using in-depth interviews [IDIs]. With the assistance of the nurses, two (2) out of the 4 authors carried out the interviews, visiting all 19 wards and 5 units, and interviewed respondents. During each interview session, one author served as the interviewer while the other took notes and tape-recorded the conversations. The IDI guide containing open-ended questions with probes was designed by the 4 authors and validated through pre-test in a secondary health facility in Nsukka local government area, Enugu state, Nigeria. Feedback from the pre-test helped to address a few technical concerns before the main study. Each interview was designed to last for an hour with provision for an extra 15 min in the case of the informal caregivers switching roles between responding to questions and attending to patients. The entire process of data collection lasted for about a month (July-August 2018). Interviews were conducted either in English or Igbo languages, and the data collectors showed they were proficient in both languages.

The content of the IDI guide is a reflection of the themes we have presented in this article. They include questions on the type of illness of the patient being taken care and the length of stay of the informal caregiver, daily and weekly routine activities of care, impact of the routine activities on several areas of the caregiver’s socioeconomic wellbeing and health, supportive or unsupportive conditions in the hospital, roles played by other support systems, suggestions for improvement, etc. All questions were open-ended, which allowed respondents to express themselves the much they could.

**Data analysis**

The audio records were all transcribed in English language and also compared with information in the notes. Transcripts were read thoroughly and the narratives were manually coded into parent and child nodes in line with thematic analysis. The parent nodes captured responses that fall under the main theme which were the main questions, while child nodes reflected responses to the sub-themes, usually the probes under each main question. This process was done for each of the 24 transcripts. Afterwards, we designed an analysis spreadsheet using Microsoft Excel. All respondents and their demographic details appeared in the heading of each column, while the themes and subthemes took the rolls. We carefully picked quotes that relate to each theme and sub-theme and placed accordingly in the spreadsheet. A summary of the responses of each respondent was made at the end of each roll.

Owing to the essence of rigour in qualitative research, the transcripts and analysis spreadsheet alongside the protocol of the study were handed to two scholars in health systems in line with peer debriefing (Babbie, 2010). They gave comments which we reviewed, discussed, addressed and incorporated with the study goals in mind. Following coherence and conciseness, we finally summed all themes into three categories.
to include, ordeals of informal caregivers, exacerbating conditions, and steps to improve coping capacities. These three thematic categories are extensively discussed in the results section of this article, even though we presented few quotes that either provide a summary of the trend of responses of respondents or carry unique expressions.

**Theoretical underpinning**

We used phenomenology as the theoretical underpinning for understanding and analysing our data. Attention was given to the phenomena under study, which is caregiving experiences of patients’ caregivers. Our understanding of the phenomena was sourced from the lived experiences of the caregivers in the context of their respective worlds (Neubauer et al., 2019). As respondents narrated their experiences, we looked out for their ordeals as experienced both in and out of the facility, which we believe gives a rich and classic understanding of the phenomena. This was how we could identify their ordeals in the context of four layers – the hospital, workplace/school, social/religious setting, and their families. These four layers are no doubt the actual worlds of the respondents, and are connected to the impacts from caring for patients. With understanding drawn from their experiences of caregiving and the interactions with the above-stated four layers, we could achieve a robust view of what the caregivers go through while taking care of their sick loved ones. Finally, our analysis was done in thematic clusters as advised by phenomenology. The essence is to systematically or procedurally communicate the robust understanding of the phenomena (Braun & Clarke, 2006; Creswell & Creswell, 2018).

**Results**

**Sociodemographic characteristics**

On gender, 92% of the caregivers were females, while the rest were males. Same 92% indicated to have assistance from one or two family members or friends with their caregiving responsibilities, although they stated that the assistance was not regular. 75% of the respondents indicated to be married and same percentage of persons indicated to have a job that fetches income. Of those that earn an income, 62.5% earned above the then minimum wage of Nigeria (N18,000 or $50) monthly. We had more respondents (58%) above 30 years. All 24 respondents claimed to be Christians and have spent at least a night or more with their patients in the facility. See Table 1 for summary presentation of the respondents’ sociodemographic information.

**Challenges of informal caregiving**

Respondents were allowed to freely express the situation of informal caregiving. Generally, responses showed that the exercise is indeed a strenuous one and could cause them losses in several areas of their lives. See their responses below:
Anybody that is sick is just like a baby. The drip might finish at night, so you don’t sleep; in such case, you have to call the nurse or the doctor […] I have to be awake to take care of him. I take him to the toilet, and monitor him, else he will soil the place… Because I am human, I only sleep for a little while (Female Caregiver, 44 years, Male surgical ward – 006)

The responses also implied that a considerable part of caregiving is borne by the informal caregiver, while nurses and doctors most often stick to clinical roles.

Nurses and the doctors will not bath your relative for you. You are the one responsible for feeding your patient, and to buy what he needs to eat. I go outside to buy drugs. I assist him

Table 1. Summary of sociodemographic data of informal caregivers.

| Sociodemographic                        | Frequency | %    |
|-----------------------------------------|-----------|------|
| Gender                                  |           |      |
| Male                                     | 2         | 8    |
| Female                                   | 22        | 92   |
| Total                                    | 24        | 100  |
| Acknowledgement of social support        |           |      |
| Yes                                      | 22        | 92   |
| No                                       | 2         | 8    |
| Total                                    | 24        | 100  |
| Marital status                           |           |      |
| Married at present                       | 18        | 75   |
| Not married at present                   | 6         | 25   |
| Total                                    | 24        | 100  |
| Income earner                            |           |      |
| Yes                                      | 18        | 75   |
| No                                       | 6         | 25   |
| Total                                    | 24        | 100  |
| Earn above minimum wage                  |           |      |
| Yes                                      | 11        | 61   |
| No                                       | 7         | 39   |
| Total                                    | 18        | 100  |
| Age                                      |           |      |
| >30 years                                | 14        | 58   |
| ≤30 years                                | 10        | 42   |
| Total                                    | 24        | 100  |
| Religion                                 |           |      |
| Christianity                             | 24        | 100  |
| Non-Christianity                        | 0         | 0    |
| Total                                    | 24        | 100  |
| Ever spent a night in the facility       |           |      |
| Yes                                      | 24        | 100  |
| No                                       | 0         | 0    |
| Total                                    | 24        | 100  |
with going to the toilet, and I do these things round the clock (Female Caregiver, 28 years, Male medical ward – 002)

Besides the issue of poor sleep and need for rapid response to the needs of patients which most of the respondents reported as strenuous, the problems of inadequate caregiving support from health workers as well as the considerable direct and indirect economic costs of informal caregiving were also reported. At the extreme, it could be depressing and catastrophic for those with lean or no dependable sources of income and those who have to return to their jobs to earn money. Commuting to facilities that are far from their homes was considered challenging and an additional economic burden. More so, informal caregivers sometimes feel like they have lost some of their freedoms.

The distance from my house to the hospital is a long one. It will take me N500 to come to the hospital using a motorcycle transport. I buy many drugs, plenty of them. I have bought blood for him once and the doctors say he needs another blood. I do this daily. My shop has been locked, which means no income. I need financial assistance; we have been billed and I do not have any money. How do I continue this way? (Female Caregiver, 48 years, Special care ward – 007)

Lastly, the social impacts of informal caregiving were mentioned, and respondents wished they were never trapped in their present conditions. They especially lamented the consequences on home keeping and their academics (for those schooling).

How can I do those things: I can’t do them? I don’t go to church or visit friends; I can’t do them when I have someone in the hospital that is dying (Female Caregiver, 31 years, Female medical ward – 004)

However, impacts on home keeping differed for respondents who had children who were already grown. The reason is that grownup children can fend for themselves, which significantly reduces the need to regularly commute between the facility and home.

Conditions that exacerbate the challenges of informal caregiving

We discovered that informal caregiving could be more strenuous for some persons than the rest. Here, we highlight the conditions responsible for the variation of ordeals experienced by informal caregivers. First, we discovered that the severity of sickness could determine how strenuous informal caregiving can be. Also, it could be frustrating for those who newly commenced taking care of their admitted sick loved ones.

My husband has a stroke. He cannot move around. I do everything for me. If I am not here, he cannot survive. The nurses and doctors would not do these things I am doing for him (Female Caregiver, 45 years, Male medical ward – 001)
Those with support networks like siblings, spouses, relatives, church members and friends could take turns in rendering informal caregiving to the sick or can help with some of the responsibilities. Such arrangement afforded them the opportunity of attending to some other needs of theirs or lessens the burden of caregiving.

*My two elder sisters are helping me. One of them just left some minutes ago. I will be here till evening when the other will come and take over. We do it that way so that we can still attend to our private businesses while taking care of our father* (Female Caregiver, 33 years, Neurology private ward – 010)

While money (income) could influence the severity of the ordeals faced by the informal caregivers, age was perceived to wield less influence since the old and young suffered various peculiar conditions while taken care of their sick loved ones.

**Improving the coping capacities of informal caregivers**

It might not be feasible to completely remedy ordeals faced by informal caregivers in health facilities. However, we believe that their coping capacities can be enhanced, and social workers could play important roles. From respondents’ narratives, we identified areas calling for attention. Most respondents wished for more support from their social networks, as those who were already benefiting from it encouraged the practice. The role of religion was equally hailed.

*My pastor supports me with prayers and encourages me with words, and my relatives visit sometimes and give me food or money. My friends do call regularly to check on us. And some church members contribute money for me. They all give me hope* (Female Caregiver, 31 years, Private ward – 012)

We discovered that deficiencies in infrastructure and amenities that could aid relaxation, poor attitude and responsiveness of health workers, and weak financial coverage could affect informal caregivers. See narratives below:

*The sockets should be replaced so we can charge our devices comfortably. They should put a good television and subscribe to good TV stations. They should also try to clean the environment regularly. The building is fine, but they need to make it comfortable for patients and their caregivers* (Male Caregiver, 23 years, Intensive Care Unit – 017)

On poor responsiveness of health workers, a respondent explained:

*I don’t know why it is so common with public facilities not to respond quickly to the needs of patients. My mum was to take her drugs. I had to remind the nurse on duty severally. They kept telling us to wait until the doctor comes. If not because of the money, one would have gone to a private facility where the services are quicker* (Female Caregiver, 28 years, Accident and Emergency Ward – 022)
Finally, previous quotes show that informal caregivers mobilise financial assistance from support networks. However, there is need to consider an institutional system of identifying those who are poor and might be lacking viable support systems.

*If there is how they can identify some of us who are poor and at least try to reduce our bill, it will be fine. It will go a long way to reduce the burden. It is not easy with me* (Female Caregiver, 33 years, New Born Special Care Unit – 019)

**Discussion**

Strengthening hospital services in Nigeria is one goal that has been pursued with a greater focus on mainstream health workers and the services they render to patients. Complementary roles to the services rendered by the mainstream health workers are less talked about, particularly in LMICs. Our research identifies informal caregivers of patients as a silent but important part of the efficiency of hospital services. While patients rely on mainstream healthcare for health services, they also rely on their informal caregivers for economic and psychosocial support, like, bathing, washing, mobility, feeding, monitoring of healthcare and health improvement, etc. It could be estimated that the bulk of the patient’s recovery is dependent on who spends time with him or her the most, and we find informal caregivers in this position. Unfortunately, while there is a paucity of literature in this regard, we discovered that available studies within the clime of Nigeria report poor consideration of informal caregivers within the healthcare framework (Gabriel et al., 2019; Inogbo et al., 2017). Therefore, our study seeks to scale up conversations on this important aspect of healthcare, with hopes that health policymakers and providers will make deliberate efforts in considering their welfare and concerns.

The cost of informal caregiving manifests in several consequences to include health, economic and social. Respondents generally attested to the burden of informal caregiving on their health, as most recounted experiences of perpetually losing sleep. They lose sleep because of the need to always stay awake in the event of the discomfort of their sick loved ones. This is besides the psychological stress most of the respondents reported, which threw them into some mental disturbances. It is a known fact that sleep and psychological disturbances could make one vulnerable to a wide range of illnesses. Informal caregivers who turned out becoming patients themselves are discussed in some studies (Adelman et al., 2014; Gabriel et al., 2019). Yet it was discovered that despite the poor sleep conditions reported by the respondents they had no good bed in the wards to lay their heads. Absence of good beds or a relatively comfortable facility for sleep for caregivers was found to have exacerbated existing difficult conditions for them while at the hospital. This should be a concern for social workers and should form a part of their advocacies and resources to mobilise.

Phasing out out-of-pocket expenditures on healthcare is a key ambition for Universal Health Coverage (Onwujekwe et al., 2010). While respondents lamented the high medical bills of their loved ones, causing them to wish for a reduction, most respondents
equally lamented the closure of their businesses as a result of taking care of their sick loved ones, as well as transportation cost for those that live far from the facility. As a result, some of them had to go into borrowing which they complained affected them psychologically. The issue of health insurance is suboptimally addressed in Nigeria, and the poor tend to suffer more the impacts of paying out-of-pocket, including catastrophic health expenditure (Onwujekwe et al., 2020). There are ongoing conversations in the scholarly space on how to insure persons in informal groups (Aregbeshola & Khan, 2018; Onoka et al., 2013). An accomplishment of a social health insurance scheme will be meaningful to provide financial aids for informal caregivers who shut their businesses or stay out of their jobs to attend to their sick loved ones. Such aids can come in forms of accessible social health insurance packages for patients who might not have the wherewithal to be enrolled in the formal health insurance scheme, and it can also be used to provide supportive allowances to the informal caregivers (Pressly, 2018).

Furthermore, it is established that informal caregivers are burdened with caring for patients. Findings show that such burden could affect their productivity and presence at the workplace. We are of the opinion that social workers can provide supportive services to the affected informal caregivers by officially reaching out to their workplaces, explaining the conditions of the informal caregivers, and providing updates about their welfare and the possible time they could fully return to work. Such supportive service will not only provide relief to the informal caregivers, but authenticate their claims about informally caring for their hospitalised loved ones.

Differently, some of the respondents who had cooperative social networks had the understanding to take turns in caring for their sick loved ones or they wish for the recovery of the patient to the point of less dependence on them. Therefore, in planning for informal caregivers, one could aggregate supports from relevant support networks of the primary informal caregiver. Social workers could therefore pay attention to these support networks as a part of the strategy to alleviate the concerns of informal caregivers.

Socially, informal caregivers could no longer attend social events like wedding ceremonies and funerals. However, while they could readily trade attendance at social events for taking care of their sick loved ones, those with home keeping responsibilities like childcare, found it extremely difficult. Some respondents mentioned leaving the facility at nights to their homes to be with their children most especially and returned to the facility when it is morning. This means that offering care in the one hand leads to deprivation of care in the other. Informal caregivers who had grownup children or no child at all had the caregiving responsibilities less burdensome. Grownup children could take care of themselves which saves the informal caregiver the strain of moving between home and the facility. However, they complained of the tendency of such gap weakening the family bond. Those without children but who are students complained about their caregiving responsibilities affecting their academics. It is therefore important that informal caregivers are from time to time assessed by social workers and other psychosocial service professionals in the facility, to underscore the extent of the burden they bear and how they could be helped. How family responsibilities among other responsibilities could affect informal caregivers is borne in some studies (Hu et al., 2016; Kaur et al., 2018; Liang et al., 2018).
Respondents wished for an improved hospital environment in terms of sanitation and amenities. They complained about sockets not working and no televisions with good TV stations to watch. They also wished for a better attitude of health workers toward work, with specific reference to the manner they verbally address the caregivers and rate of responsiveness to the needs of the patients. We discovered that owing to the filial culture of Nigerians which include caring for the sick (Nayak et al., 2014), replacing informal caregivers with some hospital staff or other paid caregivers might not be entirely feasible. Thus, enhancing the coping capacities of informal caregivers will make sense, and doing so falls within the purview of social workers. As a matter of urgency, current social workers in health facilities in Nigeria can commence advocacies on this issue at the levels of the facility and overall healthcare management in the country. While a curriculum approach will make sense, especially in the training of budding social workers in tertiary institutions, there is need for AMSWON to consider in-service training on this subject for current practising medical social workers.

Sequel to the foregoing, we know that the several suggestions we have made with regards to what social workers can do to scale up succour and wellbeing for informal caregivers are feasible, yet challenged. These challenges could either be proximate or remote. While the proximate challenges could be resolved by the social workers working in the facility, the remote drivers are off the remit of what these social workers can address. However, both categories of challenges could be interwoven. For instance, a fundamental challenge faced by Nigerian social workers within the hospital setting is a professional identity which has to do with other healthcare professionals understanding the roles the social worker is expected to play. Of course, professional identity is fastened to the professionalisation of the profession by an act of law, which is clearly a remote challenge and can only be addressed at a top-government level. Notwithstanding, within the hospital setting these social workers can pressure hospital authorities into a meeting where they discuss professional boundaries and responsibilities. The outcome of such forum will help lift the face of the profession within the hospital and give more grounds for them to be heard which makes advocacy-related solutions to the many challenges faced by informal caregivers easier to achieve. This is because respect and regards are essential to be heard and the taking of actions on what is heard.

In another instance, there is the proximate challenge of weak knowledge about the social work profession among hospital service users which translates into low uptake of social work services even when available (Okoye, 2019; Okoye & Agwu, 2019). Thus, social workers within the hospital setting should devise measures to inform hospital service users about their roles in the hospital which include how they could make informal caregiving less worrisome. We think that one of such measures could be having a social work gatekeeper at the point of receiving patients into the hospital. The gate-keeper would be responsible for educating the service users on the importance of social work services to the experiences of informal caregiving among other events they are likely to face while in the hospital.

As revealed in literature (Hu et al., 2016; Sharma et al., 2016) females comprised the bulk of informal caregivers in our study and their gender roles in home keeping exceptionally played out either in providing succour for the patients or severely affected by taking care of the patients. Additionally, since all informal caregivers experienced one
form of burden or the other, and in most contexts, they experienced common burden e.g. health implications, we could not establish the influence of age as suggested by Liang et al. (2018). Perhaps, it could be because we had no respondent above 50 years which would have represented the older crop of adults. This gap could be explored in future studies on this subject.

**Synopsis of the implications of the study for social work**

Our study has clearly shown the importance of social workers in scaling up the efficiency of health services’ delivery through paying attention to the concerns of informal caregivers of patients in Nigeria. Our findings show that informal caregivers, although neglected, form a crucial part of the health system by playing significant and indispensable roles in aiding the recovery of patients. We also discovered that the closest group of health professionals to informal caregivers are supposedly the social workers, even though nurses can as well be found within this remit. However, our findings reveal many challenges faced by social workers which tend to have impacted their professional responsibilities to the informal caregivers.

There is poor recognition of social workers within the studied health facility, which is understandably an implication of the lack of professionalisation of social work by an act of law in Nigeria. Resultantly, non-social workers are employed to perform social work jobs, professional boundaries are not clear enough, and health service users tend to be unaware of social work services within the hospital. We consider these gaps as the primary challenges of social work in Nigeria’s healthcare system, with impacts on quality care provision for informal caregivers.

Nevertheless, it is encouraging that at least there is a provision for the employment of social workers in health facilities, even though such provision is only available at the secondary and tertiary level-facilities. We suggest that galvanising AMSWON which is the umbrella body of medical social workers in Nigeria or hospital-based social work unions to chart these recommendations will make sense and appears the most feasible action to take. They can commence the process of dialogue with other health professionals on professional responsibilities and boundaries, set up social work gate keepers in facilities to advertise the roles of the profession to service users, and in-service training of current medical social workers on care provision for informal caregivers. The solutions to professionalisation and employing just trained social workers to man social work jobs are extremely political, and in prevalent non-rule following contexts in LMICs, navigating through such political complexities is often difficult and not feasible (see Khan et al., 2019). This is why we argue the need to pursue feasible strategies to scale up the profession’s relevance in healthcare setting, and pay attention to the care of patients’ informal caregivers.

**Limitations of the study**

Our study did not consider the voices of health and social workers in validating the experiences of the informal caregivers. Thus, we recommend that future studies should explore insights of health and social workers on this issue. Furthermore, the focus of our study was on a public
facility and our findings were limited to only one hospital. It could be that these experiences might be different in private health facilities or other public health facilities. Therefore, we recommend that in subsequent related studies, the private sector should be captured.

**Conclusion**

In all, we conclude that informal caregivers in hospitals should be paid attention to. They need to be documented, attended to by social workers and their caregiving experiences in the hospital deserve to be monitored by hospital authorities. Health policymakers and providers should capture them in healthcare policies and administration since their roles are complementary to the efforts of the health workers in the treatment of patients. A national policy for the care of informal caregivers will make sense, amidst other issues we raised like financial inclusion for the poor or indigent, and improving the infrastructure in public hospitals. Social workers were found indispensable in the pursuit of this goal, yet informal caregivers appeared largely unaware of their importance. This calls for intense awareness creation of social work services across health facilities, including at structural levels of healthcare management in Nigeria. We are convinced that a comprehensive approach to addressing the concerns of informal caregivers will help strengthen the health system of Nigeria in view of achieving global health goals.

**Authors’ contributions**

All authors contributed to developing and testing the interview instrument. HA and NC conducted the interviews, while all authors performed the coding and reviewed the coding for major themes. PA and NC conducted in-depth analysis of coded materials and wrote the first draft manuscript, with input and final review by HA and NA. NC and PA led the overall study.

**Ethics**

The study protocol was reviewed and approved by the Health Research Ethics Committee [HREC] of UNTH: NHREC/05/01/2008-FWA00002458-100002323.

**Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The author(s) received no financial support for the research, authorship and/or publication of this article.

**Acknowledgements**

We profoundly acknowledge the respondents for this study, and the health workers that helped us navigate the search for respondents at the study site. Also, we appreciate the incisive comments and rigorous review process led by the anonymous reviewers and editor which improved the quality of the article.
References

Adelman, R., Tmanova, L., Diana, D., Sarah, D., & Lachs, M. (2014). Caregiver burden: A clinical review. *The Journal of American Medical Association*, 311(10), 1052–1060. 10.1001/jama.2014.304

Agwu, P., & Okoye, U. (2021). Social work and COVID-19: A gap in Nigeria’s intervention. *International Social Work*, 64(5), 761–770. https://doi.org/10.1177%2F0020872820980799

Ahmed, H., Alhassan, S., Alshammari, F., & Ogbonna, B. (2017). Social welfare scheme; a neglected component of public health care services in Nigeria. *MOJ Public Health*, 5(3), 101–104. https://doi.org/10.15406/mojph.2017.05.00132

Aregbeshola, B., & Khan, S. (2018). Predictors of enrolment in the National Health Insurance Scheme among women of reproductive age in Nigeria. *International Journal of Health Policy and Management*, 7(11), 1015–1023. https://dx.doi.org/10.15171/ijhpm.2018.68

Babie, E. (2010). *The practice of social research* (12th ed.). Wadsworth Cengage Learning.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research Psychology*, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Creswell, J., & Creswell, J. (2018). *Research design: Qualitative, quantitative and mixed methods approaches* (5th ed.). Sage.

Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information*, 45(4), 483–499. https://doi.org/10.1177%2F0539018406069584

Eke, C. (2015). *Healthcare resource guide: Nigeria*. https://2016.export.gov/industry/health/healthcareresourceguide/eg_main_092285.asp

Federal Ministry of Health. (2020). *Hospital services division*. https://health.gov.ng/index.php?option=com_content&view=article&id=129&Itemid=495

Gabriel, I., Aluko, J., & Okeme, A. (2019). Caregiver burden among informal caregivers of women with breast cancer. *Biomedical Journal of Scientific and Technical research*, 15(3), 1–9. http://dx.doi.org/10.26717/BJSTR.2019.15.002704

Hu, X., Dolansky, M., Hu, X., Zhang, F., & Qu, M. (2016). Factors associated with the caregiver burden among family caregivers of patients with heart failure in southwest China. *Nursing and Health Sciences*, 18(1), 105–112. https://doi.org/10.1111/nhs.12253

Igwe, I., Agwu, P., Okoye, U., Onyeneho, N., Aronu, N., & Odii, A. (2019). Controlling malaria spread with insecticide-treated nets: Reactions trailing usage and mortality consequences in Anambra state, Nigeria. *International Journal of Community and Social Development*, 1(2), 169–183. https://doi.org/10.1177%2F2516602619855231

Inogbo, C., Olotu, S., James, B., & Nna, E. (2017). Burden of care amongst caregivers who are first degree relatives of patients with schizophrenia. *The Pan African Medical Journal*, 28(284), 1–10. https://doi.org/10.11604/pamj.2017.28.284.11574

Iroanusi, Q. (2019, May 9). Senate summons minister over state of facilities in Nigerian teaching hospitals. *Premium Times*. https://www.premiumtimesng.com/health/health-news/329121-senate-summons-minister-over-state-of-facilities-in-nigerian-teaching-hospitals.html

Kaur, P., Kaur, S., Bhalla, A., Katyal, P., Raavi, K., Kaur, R., Bhangru, R., & Kaur, R. (2018). Strain among the family caregivers of patients with stroke. *Journal of Perioperative & Critical Intensive Care Nursing*, 4(2), 1–4. 10.4172/2471-9870.10000144
Kent, E., Rowland, J., Northouse, L., Litzelman, K., Chou, W., Shelburne, N., Timura, C., O’Mara, A., & Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, 122(13), 1987–1995. https://doi.org/10.1002/cncr.29939

Khan, M., Andreoni, A., & Roy, P. (2019). Anti-corruption in adverse contexts: strategies for improving implementation. https://ace.soas.ac.uk/wp-content/uploads/2019/12/ACE-BriefingPaper006-NG-191202.pdf

Lee, J., Barlas, J., Thompson, C., & Dong, Y. (2018). Caregivers’ experience of decision-making regarding diagnostic assessment following cognitive screening of older adults. *Journal of Aging Research*, 2018(1), 1–9. https://doi.org/10.1155/2018/8352816

Liang, Y.-D., Wang, Y.-L., Li, Z., He, L., Xu, Y., Zhang, Q., You, G.-Y., & Mi, X.-H. (2018). Caregiving burden and depression in paid caregivers of hospitalised patients: A pilot study in China. *BMC Public Health*, 18(53), 1–7. https://doi.org/10.1186/s12889-017-4563-6

National Cancer Institute. (2019). *Informal caregivers in cancer: Roles, burden, and support: Health professional version*. https://www.ncbi.nlm.nih.gov/pubmed

Nayak, M., George, A., Vidyasagar, M., & Kamath, A. (2014). Quality of life of family caregivers of patients with advanced cancer. *IOSR Journal of Nursing and Health Science*, 3(2), 70–75. https://www.iosrjournals.org/iosr-jnhs/papers/vol3-issue2/Version-1/L03217075.pdf https://doi.org/10.9790/1959-03217075

Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, 8(2), 90–97. https://doi.org/10.1007/s40037-019-0509-2

Northouse, L., Katapodi, M., Schafenacker, A., & Weiss, D. (2012). The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Seminars in Oncology Nursing*, 28(4), 236–245. https://doi.org/10.1016/j.soncn.2012.09.006

Ogunyemi, D. (2015, November 9). AMSWON seeks more medical social workers in hospitals. Daily Trust. https://dailytrust.com/amswon-seeks-more-medical-social-workers-in-hospitals

Okafor, A., Onalu, C., Ena, J., & Okoye, U. (2017). Social work in healthcare setting. In U. Okoye, N. Chukwu, & P. Agwu (Eds), *Social work in Nigeria: Book of readings* (pp. 145–156). University of Nigeria Press Ltd.

Okoye, U. (2019). Health care social work in Nigeria. In R. Winnett, R. Furman, D. Epps, & G. Lamphear (Eds), *Health care social work: A global perspective* (pp. 149–161). Oxford University Press.

Okoye, U., & Agwu, P. (2019). Sustainable and healthy communities: The medical social work connection. *Journal of Social Work in Developing Societies*, 1(1), 30–45. https://journals.aphriapub.com/index.php/JSWDS/article/view/663/646

Olajire, B. (2020). *Universities offering social work in Nigeria (Admission Requirements)*. https://servantboy.com/universities-offering-social-work-nigeria/

Onalu, C., Agwu, P., Okoye, U., & Agha, A. (2020). Mother-to-child transmission of HIV and utilization of preventive services in Anambra south senatorial zone, Nigeria: Practice considerations for social workers. *International Social Work*, 0(00), 1–15. https://doi.org/10.1177%2F0020872820901748

Onoka, C., Onwujeke, O., Uzochukwu, B., & Ezumah, N. (2013). Promoting universal financial protection: Constraints and enabling factors in scaling-up coverage with social health insurance in Nigeria. *Health Resource Policy System*, 11(20), 11–20. https://doi.org/10.1186/1478-4505-11-20

Onwujeke, O., Dike, N., Uzochukwu, B., & Ezoeke, O. (2010). Informal payments for healthcare: Differences in expenditures from consumers and providers perspectives for treatment of malaria in Nigeria. *Health Policy*, 96(1), 72–79. https://doi.org/10.1016/j.healthpol.2009.12.014
Onwujeke, O., Orjiakor, T., Hutchinson, E., McKee, M., Agwu, P., Mbachu, C., Ogbozor, P., Obi, U., Odii, A., Ichoku, H., & Balabanova, D. (2020). Where do we start? Building consensus on drivers of health sector corruption in Nigeria and ways to address it. *International Journal of Health Policy and Management, 9*(7), 286–296. 10.15171/ijhpm.2019.128

Pressly, L. (2018, December 21). *The ‘angel’ who secretly pays patients’ hospital bills.* BBC News. https://www.bbc.com/news/stories-46637822

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity, 52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Sercekus, P., Besen, D., Gunusen, N., & Durmaz, A. (2014). Experiences of family caregivers of cancer patients receiving chemotherapy. *Asian Pacific Journal of Cancer Prevention, 15*(12), 5063–5069. https://doi.org/10.7314/apjcp.2014.15.12.5063

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people living with mental illnesses. *World Journal of Psychiatry, 6*(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

Utne, I., Miaskowski, C., Paul, S., & Rustoen, T. (2013). Association between hope and burden reported by family caregivers of patients with advanced cancer. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer, 21*(9), 2527–2535. https://doi.org/10.1007/s00520-013-1824-5

Yigitalp, G., Surucu, H., Gumus, F., & Evinc, E. (2017). Predictors of caregiver burden in primary caregivers of chronic patients. *International Journal of Caring Sciences, 10* (3), 1168–1180. http://www.internationaljournalofcaringsciences.org/docs/7_cumus_original_10_3.pdf