Lived Experiences of Migrating Informal Caregivers

POLICY BRIEF

ALLEVIATING THE PLIGHT OF INFORMAL CAREGIVERS WHO "HANG AROUND" IN NIGERIAN TERTIARY HEALTH FACILITIES

EXECUTIVE SUMMARY

Informal caregivers (ICs) are at the heart of Universal Health Coverage (UHC) as they supply valuable labour to the health system. However, they face significant challenges, which can be worsened by the circumstances under which they support patients on admission. This policy brief reported findings from a study on the lived experiences of ICs who travel to an urban tertiary health facility to support sick relatives. It identified why ICs stay in the hospital while supporting hospitalisation care, the consequences of their challenges, and outlined what must be done to alleviate their plight in Nigerian health facilities.

KEY MESSAGES

- ICs with hospitalised relatives are constrained to stay in/around the hospital because daily movement to and from their regular place of residence is difficult, costly, inefficient, impractical or impossible.
- Although ICs also desire to be near sick elatives, hospital policy inconsistency, the practice of co-optive task shifting, the patient's clinical status, complementary ideas of care and the unaffordability of formal hospitalisation care further contributed to why they hang around.
- The challenges faced by ICs have negative impact on their health with additional consequences for health workers and the hospital.
- ICs face many challenges related to health and wellbeing, facility deficiencies, social and economic issues, security and safety, relational and attitudinal problems and hygiene maintenance.
- Alleviating the plight of ICs will involve prioritising their wellbeing. This includes assisting them prepare for long-distance referrals, improving facilities, training staff and reversing the depency on ICs by leveraging technology for improved efficiency in tertiary hospitals.

SCOPE OF PROBLEM

Informal Caregivers (ICs) are individuals, usually family members, relatives or friends, who provide unpaid supportive care to those unable to care for themselves because of health challenges or hospitalisation[1]. ICs perform caretaker duties[2] by helping inpatients maintain emotional balance, assisting with activities of daily living, medicine administration, appointments, communicating with healthcare professionals and general navigation of the health system.[3-5] Some even engage in specialised care tasks, such as taking samples to the laboratory, emptying urine bags and defecation basins and moving immobilised patients.[5,6]

A common site after-dark at one of the hospital's busiest wards.

In sub-Saharan Africa, ICs are perceived as being at the heart of Universal Health Coverage (UHC) and supply valuable labour to the health systems.[7] Despite their critical roles, their place in the health system remains unclear as professional care providers often view their presence as counterproductive.[4,8] More so, the experiences of ICs vary, depending on support, education, and the context of participation in informal caregiving. Recorded experiences in different contexts include vulnerabilities, illnesses,[9] decreased quality of life,[10] lack of support,[11] unmet financial, social, training and information needs,[12] and psychosocial issues.[7]

The Lived experiences of migrating informal caregivers in a tertiary health facility: Understanding and action for health systems improvement in Nigeria study (or LEMIC Study) explored a unique context of informal caregiving in Nigeria. Specifically, the LEMIC study documented the experiences of internally migrating informal caregivers, people who travel far from home to care for hospitalised patients while stationed in/around an urban tertiary health facility in Southwestern Nigeria. An ethnographic method of inquiry was used to collect data. A total of 75 participants were interviewed:

Informal caregiver (n=21)	Inpatients (n=15)
Hospital staff (n=36)	Ad-hoc/paid caregivers (n=3)

WHY ARE CAREGIVERS "HANGING AROUND" AND LIVING IN/AROUND THE HOSPITAL?

1. Care Mobilities

Informal caregivers accompanying sick relatives to the hospital are constrained to stay and hang around because of specific movements associated with care-seeking, termed care mobilities. Care mobilities take ICs far from home to places where daily commuting is difficult, costly, inefficient, impractical or impossible. More than half of the ICs interviewed in this study came from outside the state where the healthcare facility is located.

2. Proximity to Hospitalised Relatives

Proximity – or being near in space, time and relationship – to hospitalised patients shapes the presence of ICs. Reasons for proximity include the internalised role of supportive carers and the entrenched belief that the absence of caregivers implies the abandonment of inpatients. Also relevant to proximity are fear of missing out on the needs of their relatives, distrust of healthcare workers, the need to boost the morale of patients and participation in the space of a community of informal carers in the health facility.

3. Policy Contradictions

Policy contradiction between established rules and everyday care practice contributes to ICs' stay with inpatients. The hospital maintains a visitation policy but operates an unwritten rule that demands that relatives hang around as part of the process of providing hospitalisation care and services. Thus, an IC is expected to be on the ground to help the patient, although established rule is against it.

4. Co-optive Task Shifting

Co-optive task shifting involves transferring certain roles to ICs by incorporating their labours into hospitalisation care. The domain of duties within the health system is redefined with the caregiver as a significant actor because of health system problems and institutional failures such as staff shortages which has created a vacuum that informal caregivers are constrained to fill.

5. Clinical Status of Inpatients

The patient's clinical status determines whether they can manage the practicalities of hospitalisation alone. Patients clinically determined to be unstable or in critical or dire condition need supportive care the most. This is because hospitalisation often involves a settlement stage when life-saving and stabilisation interventions happen, and critical decisions are made, making relatives' presence necessary.

6. Complementary Philosophies of Care

Two philosophies of care influence the temporary residence of caregivers in the hospital. The first is based on the culture of care in the Nigerian society, whereby relations are expected to support one another. Thus, hospitalisation and associated problems is not for the sick to bear alone. The second derives from the practice of holistic care in the hospital. Health workers wish to involve family members in caregiving to achieve optimal clinical outcomes for inpatients.

7. Unaffordability of and Raising Money for Hospitalisation Care

Hospitalisation is costly for many low-income earners and poor people referred to tertiary hospitals for specialised care. The high cost of staying also applies to relatives who often engage in mobilising resources needed for the care of inpatient through the duration of hospitalisation.

WHAT CHALLENGES DO CAREGIVERS FACE, AND HOW DO THEY IMPACT THEIR LIVES?

The study shows the complexity of being an IC while staying in/around the hospital and reveals the burdensome character of their lived experiences.

1. Health and Wellbeing

Caregivers experienced health and well-being challenges, including stress, bodily breakdown, weakness, pain, sleeplessness, and poor feeding. They also experienced mental and psychological distress as they reported feeling sad, unhappy, angry, paranoid, and aggressive towards the situation. They are also at risk of infection and illness because of their presence and prolonged stay in the hospital.

2. Health Facility

The hospital environment is not conducive for caregivers as they experienced challenges navigating the facility while exposed to harsh weather, noise and smell. The hospital staff reported that caregivers use hospital spaces indiscriminately because of limited access to accommodation and toilet facilities, through how they appropriate spaces and disrupt regular hospital operations. These have significant implications for both human and environmental health.

3. Social and Economic Issues

There were challenges with social issues, including loss of livelihood, religious routines and commitments, support fatigue, patient abandonment, absenteeism, and social isolation due to prolonged stay in the hospital. Financial constraint is the most dominant dimension of economic challenges experienced by ICs. They reported accumulated indebtedness and perceived wastage of their limited resources while supporting hospitalisation care.

4. Security and Safety

The ICs were exposed to security and safety problems during their stay. The perception of the hospital community as an open community, where entry-exit control is minimal, exposed the ICs to risks, harassment, theft and fraud. Although security guards are available in the hospital, the health facility remains an open community where people come in and out at will. The security concern and risks are higher for those who sleep outside with their belongings.

5. Conflict Between Informal and Formal Health Care Workers

Relational and attitudinal issues experienced include interpersonal conflict shaped by information asymmetry, misunderstanding and language barriers. These conflicts often take violent dimensions as caregivers sometimes harass, fight or beat health workers and other staff.

6. Water, Sanitation and Hygiene (WASH)

The ICs have limited access to water, sanitary practices and good hygiene because of inadequate amenities and facilities in the hospital. In a few places with hygiene amenities, access control by the environmental health assistants makes it challenging for ICs, as those workers sometimes lock up toilets when there is a shortage of water supply.

WHAT SHOULD BE DONE TO ADDRESS THE CHALLENGES FACING INFORMAL CAREGIVERS?

1. Prioritise Caregivers' Health and Wellbeing

- Prioritise ICs' health and well-being as key actors in the Nigerian health system.
- Design and implement interventions to improve facilities, provide leisure opportunities, support caregivers' community, and promote their physical and mental well-being.

2. Education and Sensitisation

- Provide focused hospitalisation education with orientation, and planning contents at the point of referral and upon arrival in the tertiary health facilities.
- Bridge the information gap and make information available in an accessible and useful format.
- Ethically eradicate information asymmetry between ICs and formal health workers.
- Create awareness on supportive services, and encourage caregivers to subscribe to them, especially for those who can afford it.
- Train and re-train hospital staff on special caregivers' sensitivity training.
- Offer "Rapid Hospitalisation Care Support Training" for ICs.

3. Policy and Programme

- Create policies and programmes that acknowledge caregivers' role in hospitalisation care in Nigeria.
- Identify opportunities for creative synergies between ICs and the formal care workforce.
- Invest in continuing process evaluation of service delivery with the aim of improving efficiency.
- Strengthen existing initiatives designed to reduce the presence of caregivers and lessen the burden of the ones still hanging around.

4. Addressing Institutional Dysfunctions

- Correct the institutional dysfunctions that produced the care vacuum that ICs are filling.
- Intensify efforts to achieve UHC by fixing health inequalities, expanding access to health insurance and ensuring that lower levels of care function optimally.
- Improve health facilities and quality services as well as revamp the health institution by integrating disparate but interlinked services in the hospital.
- Create a conducive work environment and partner for improved funding with civil society organisations, foundations and philanthropies to support hospitalisation care.
- Reverse the dependency of tertiary health facilities on informal caregivers which necessitates leveraging technology to improve efficiency in payment and pharmacy services.

CONCLUSION

Informal caregivers are central to the care of hospitalised patients in Nigeria. Despite the limited acknowledgement of their indispensable roles and contributions, they will remain critical in the country's health system until the factors creating the gap they are filling are addressed. Therefore, neglecting those providing hospital-based informal caregiving will continue to slow down the attainment of UHC in Nigeria.

REFERENCES

1. Akinpelu, A. O., Olaleye, O. A., Odole, A. C. & Otaiku, O. A. Informal Stroke Caregivers' Satisfaction with Healthcare Services in a Tertiary Healthcare Centre in Ibadan, Nigeria. *International Journal of Caring Sciences* **7**, 148 (2014).

2. 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. *International Journal of Economy, Energy and Environment* **5,** 14-23 (2020).

3 Muliira, J. K., Kizza, I. B. & Nakitende, G. Roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients: perspective from a low-income country. *Cancer nursing* **42**, 208-217 (2019).

4 Hoffman, M. et al. Utilization of family members to provide hospital care in Malawi: the role of hospital guardians. *Malawi Medical Journal* **24**, 74-78 (2012).

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

6 Khosravan, S., Mazlom, B., Abdollahzade, N., Jamali, Z. & Mansoorian, M. R. Family participation in the nursing care of the hospitalized patients. *Iranian Red Crescent Medical Journal* **16** (2014).

7 Kisangala, E., Mbivnjo, E. L., Okeah, B. O. & Khan, M. A. Community and Informal Care Providers at the Heart of Universal Health Coverage in sub-Saharan Africa: A Position Paper. *South Eastern European Journal of Public Health (SEEJPH)* (2021).

8. Sadigh, M., Nawagi, F. & Sadigh, M. The Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda. *Annals of global health* **82**, 866-874,doi:10.1016/j.aogh.2016.06.005 (2016).

9 Donelan, K. et al. Challenged to care: Informal caregivers in a changing health system. *Health Affairs* **21**, 222-231 (2002).

10 Hilton, J., Mudzi, W., Ntsiea, V. & Olorunju, S. Caregiver strain and quality of life 6-36 Months post stroke. *South African Journal of Physiotherapy* **69,** 66-72 (2013).

11 Saritas, S. C., Kavak, F., Aksoy, A. & Saritas, S. Examination of the care burden of caregivers of oncology patients and the perceived social support from family. *International Journal of Caring Sciences* **10**, 447 (2017).

12 Khuabi, L.-A. J.-N. *et al.* The well-being of family members as informal caregivers of persons with stroke in an African context: Understanding their lived experience. (2021).

PHOTO CREDIT

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