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ORIGINAL RESEARCH

The Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda

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Abstract

BACKGROUND The severe deficit of health care workers in Uganda necessitates hospitalized patients to be cared for by a relative. These informal caregivers constitute a crucial component of patient care. Mulago Hospital in Kampala, Uganda, is one of the nation's national referral hospitals, receiving very sick patients. Although studies have been conducted on challenges facing informal caregivers in the home setting, no study has addressed the caregiver burden in the hospital setting.

METHODS A survey of 100 randomly selected informal caregivers was conducted in Mulago Hospital's internal medicine wards to evaluate informal caregivers' demographics, impact on patient care, and challenges.

RESULTS Challenges include emotional burdens, lack of sanitation, accommodation, sufficient health workers, finances, and recognition. Recommendations were given to ensure improve informal caregivers' situations.

CONCLUSIONS Despite hardships, informal caregivers recognize the importance of familial presence, thereby setting a new standard for patient care by recreating the comfort of home care in the hospital. Studying the characteristics of these care givers and more fully delineating the sacrifices they make and the challenges they faced provides the basis for a series of recommendations to hospital management aimed both at improved patient care and care of the informal caregiver.

KEY WORDS patient care attendant, informal caregiver, human resource limitation, caregiver economic burden, caregiver emotional challenges, resource-limited settings, health inequity, healthcare delivery

INTRODUCTION

Informal Caregivers. Human resources are a core component of any health care system. The World Health Organization (WHO) has set a minimum threshold of 23 doctors, nurses, and midwives per 10,000 people in an effort to reach the Millennium Development Goals.[1] However, many nations struggle to meet these recommendations, among them Uganda, which faces a severe shortage of health care workers, with only 14 doctors, nurses, and midwives per 10,000. Because of this deficit, it is common practice in Uganda for hospitalized patients to be cared for by a relative or friend who acts as a

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patient informal caregiver,[2] so titled because they have received no training for the work they perform.[3]

Mulago Hospital was founded in 1913 and is located on Mulago Hill in the northern part of Kampala, Uganda's capital. It is the nation's largest hospital and 1 of 2 national referral hospitals.[4] It also serves as the teaching hospital of Makerere University College of Health Sciences, the oldest medical school in East Africa.[5] It houses 1790 beds, but its average inpatient census is estimated at approximately 4000 patients, each ward containing thrice the number of bodies it was designed for,[2] with an annual budget of approximately $13 million USD.[6] The hospital provides patients with meals and a bed, but patients must supply their own sheets, blankets, pillows, and laundry services for garments. The hospital receives very sick, often terminally ill patients who require ample nursing care, yet is severely understaffed.[7] This deficit unofficially mandates patients to be accompanied by an informal caregiver, the spouse or child of an adult patient, and the parent or sibling of a child patient by convention. In the event that the aforementioned relative is unable to attend to the patient, another close relative is chosen.

These informal caregivers are more than willing to take on the responsibility of patient care, despite preordained financial and psychological burdens. They emanate home care in the hospital environment. As true patient advocates, they put work, education, and childcare on hold to look after their loved one. They are the caretaker, the nurse, the spokesperson, the bather, the comforter, the spiritual supporter. They work an arduous full-time job without compensation, yet they ask for nothing in return, other than that their loved one receives the needed treatment. They are the foundation of a hospital that is overcrowded, understaffed, and underfunded. In a place where everyone is struggling to make it through the day, the value of these informal caregivers too often goes unnoticed.[8]

A study has been conducted on challenges informal caregivers face in the United States,[9] as well as on the caretaker burden of patients with stroke,[10] dementia,[11] multiple sclerosis,[12] and rheumatoid arthritis[13] in various countries. One study conducted in western Uganda assessed the family caregiver burden of patients with HIV/AIDS in the home care setting of rural districts, and made recommendations for reducing this burden.[14] However, to the best of our knowledge there has not been a study holistically addressing the family caregiver burden of patients in the hospital setting, with recommendations from caregivers themselves.

The worldwide prevalence of informal caregivers renders this an issue of international relevance and an assessment of the role and associated challenges of informal caregivers as necessary. Their work greatly affects patients and their families, hospital staff, and overall hospital function. This study aimed to uncover the lives of informal caregivers at Mulago Hospital, along with their emotional and economic challenges.

METHODS

Setting. This study was focused in the internal medicine wards of Mulago Hospital, in Kampala, Uganda.

Survey Instrument. Data were collected via face-to-face interviews with informal caregivers using a 39-question survey tool that included demographics and both close-ended and open-ended questions in regard to their challenges, experiences, and recommendations. An interpreter accompanied researchers for interviews that were not conducted in English. The first 10 interviews were carefully reviewed for validity and efficacy of the survey instrument, after which the original survey instrument was reassessed and refined.

Participant Selection and Sample Size. One hundred participants were selected randomly. This number was chosen based on when the themes and concepts were exhausted. Random selection was accomplished by assigning each bed in the medical wards a number, with the numbers randomly generated electronically. Informal caregivers associated with the bed selected were approached and consent was obtained. No informal caregivers refused, and no surveyed beds were unaccompanied by an informal caregiver. The study did not include any patients who were temporarily placed on the floor.

Data Analysis. Two readers performed multiple readings of the surveys and identified major ideas and themes revealed in participants' responses. Distinctive themes and those expressed by multiple participants were examined for patterns of connection and grouped into broader categories. Consensus-coding taxonomies then emerged through discussion among all readers during serial meetings at which the coding of each transcript was compared among reviewers. For quantitative analysis, descriptive statistics were generated using JMP Version 11 software. Participants were able to choose more than

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1 response for some questions; thus percentages may total more than 100.

RESULTS

Demographics. A total of 100 participants were surveyed and their demographics are shown in Table 1.

The average age of informal caregivers was 37 ± 2.75, and 71% were female. Fifty percent of informal caregivers were of the Ganda tribe that inhabits central Uganda, including Kampala, followed by Nyankole and Soga, respectively. Ten percent were born in Masaka (130 km from Kampala), 6% in Mulago, 5% in Jinja (215 km from Kampala, in the Eastern region), and 4% in Mubende, Wakiso, and Kampala, respectively. Forty percent of informal caregivers resided in Central Uganda, where Mulago Hospital is located.

Sixty-two percent were married, 23% single, 8% divorced/separated, and 7% widowed. Seventy-five percent of the group had children, with an average of 4 children per informal caregiver. In terms of employment, 31% worked in agriculture; 26% worked in business, including tailoring, hairdressing, and shopkeeping; 14% were students; 13% worked as housewives; 6% as teachers; 4% as construction workers; 3% as drivers; 2% in law enforcement; and 1% in art.

Table 1. Demographics of Informal Caregivers

	N = 100
Average age	37 (± 2.75)
Sex	
Female	71 (71%)
Male	29 (29%)
Marital status	
Married	62 (62%)
Single	23 (23%)
Divorced/separated	8 (8%)
Widowed	7 (7%)
Origin of travel	
Central	49 (49%)
Other	24 (24%)
West	11 (11%)
East	10 (10%)
South	6 (6%)
Employment	
Agriculture	31 (31%)
Business	26 (26%)
Student	14 (14%)
House chores	13 (13%)
Teacher	6 (6%)
Construction	4 (4%)
Driver	3 (3%)
Law enforcement	2 (2%)
Art	1 (1%)

Sixty-eight percent of informal caregivers were so designated as a result of being the closest relative, 10% because of a family decision, and 8% because of having more spare time than other family members. Three percent were driven by economic reasons, namely that it is more cost effective for a family member to care for the patient than to hire someone else to do so.

Travel. There are a variety of modes of transportation in Uganda. *Boda-bodas* are motorcycle-taxis. The "taxi" or *matatu* refers to a small public bus that carries about a dozen passengers. The "bus" refers to a large public bus used for transportation across larger distances, whereas "special hires" refer to hired cabs and "government vehicles" are any vehicles owned by the government, including those from public institutions. Forty-two percent of informal caregivers arrived to Mulago via *matatu*, 31% by car, 9% by bus, and 3% by *boda*. Of the remaining 15%, 85% arrived by foot, 12% via ambulance, 2% via government vehicles, and 1% via special hires. On average, transportation took 2.5 hours and cost 51450 UG Shillings ($17.80 USD). The average annual income in Uganda is $550 USD, <$2 USD per day,[15] and 23% of the caregivers in this study indicated that they borrowed money to cover the travel expenses.

Twenty-eight percent of informal caregivers traveled alone, 28% with just the patient, 7% with the patient and at least 1 sibling, 36% with other family members, and 1% with a nurse. Ten percent stayed outside Mulago, and of that group 7% took the "taxi" to and from the hospital, with a cost ranging from 2000-4000 UG Shillings (0.69-1.37 USD) per day, 2% took *bodas*, with a cost ranging from 4000 to 6000 UG Shillings (1.37-2.06 USD) per day, and 1% used a government vehicle.

Accommodation, Food, and Expenses. Ninety percent of informal caregivers stayed at Mulago for 11 days on average, with a range of 1-60 days. While staying at the hospital, 89% slept on the hospital floor. Four percent did not provide a response, 3% returned home each evening to sleep, 2% slept in the prison barracks where members of the police force stay, 1% slept in Bwaise, an urban slum in the Central region, and 1% shared the hospital bed with the patient. Twenty-nine percent obtained meals from restaurants, 21% shared the patient's

hospital-provided meals, 18% ate at both restaurants and the hospital cafe, 12% only at the hospital cafe, 12% at home, and the remaining 8% at a combination of home, hospital cafes, restaurants, and markets.

On average, 150,840 UG Shillings ($52.19 USD) were spent on patient-related out-of-pocket expenses and 97,330 UG Shillings ($26.79 USD) on personal out-of-pocket expenses. To assist with these expenses, informal caregiver families funded 41% of informal caregivers, 24% funded themselves, and 15% were funded by a combination of family and friends.

Caretaker Duties. Caretaker duties include being present for doctor visits and feeding, cleaning, and administering medication to the patient. Other major tasks included keeping the patient company; providing counseling, physical therapy, and massage; and turning the patient to avoid bedsores. Praying and preventing the patient from escaping the hospital were also cited as caretaker responsibilities.

Impact of Fulfilling the Role of Informal Caregiver on School, Work, and Family. The impact of fulfilling the role of informal caregiver was seen in informal caregivers' work, school, and family, as indicated in Table 2.

Seventy-three percent of informal caregivers reported that their work and/or school were affected by their time at the hospital. Twenty-five percent put their jobs on hold, 21% left their farms or fishing jobs unattended, 18% suspended their businesses, and 3% left school.

Sixty-nine percent of informal caregiver families also felt affected. Thirty-five percent of informal caregivers reported "lack of care" for their own children and families, 13% felt their family lacked financial support, 10% reported their family missed their presence at home, 7% reported family concern regarding upholding the cultural expectation that family members care for their ill loved ones as opposed to hired staff, 2% reported lack of childcare and finances, and 2% reported the inability to send their children to school. Thirty-one percent reported that their family was not affected.

Patient Diagnosis. The most common recent diagnosis of patients cared for by surveyed informal caregivers was HIV/AIDS (21%) followed by severe hypertension (8%), diabetes mellitus (8%), congestive heart failure (7%), anemia (6%) and stroke (6%). The remaining 44% included a variety of diagnoses.

Treatment of Informal Caregivers and Patients by Health Workers. The treatment of informal caregivers and patients by health workers, and the explanation of the patient's condition given to informal caregivers by health workers, are indicated in Table 3.

Seventy-three percent of informal caregivers reported that the doctor fully explained the patient's situation, whereas 1% reported receiving only a partial explanation and 26% reported that the doctor did not offer any explanation. Of those who received an explanation, 72% reported having understood what was discussed. The large majority (94%) felt comfortable asking the doctor

Table 2. Impact of Role as Informal Caregivers on School, Work, and Family

	N = 100
Impact on work or school	
Unaffected	27 (27%)
Work at a standstill	25 (25%)
Cannot tend to farm/fishing	21 (21%)
Business not open/profitable	18 (18%)
Absence causes loss of income	3 (3%)
Cannot attend school	3 (3%)
Boss is angry about absence	2 (2%)
Cannot complete work on time	1 (1%)
Impact on Family	
Unaffected	31 (31%)
Lack of care	35 (35%)
Lack of financial support	13 (13%)
Missing presence of informal caregiver at home	10 (10%)
Concern upholding cultural expectation for family caregiver	7 (7%)
Lack of childcare/finances	2 (2%)
Children unable to attend school	2 (2%)

Table 3. Informal Caregiver and Patient Treatment by Health Workers

	N = 100
Quality of Patient Treatment by Health Workers	
Very well	18 (18%)
Well	65 (65%)
Moderately	14 (14%)
Badly	3 (3%)
Quality of Informal Caregiver Treatment by Health Workers	
Very well	19 (19%)
Well	64 (64%)
Average	15 (15%)
Badly	2 (2%)
Explanation of Patient Situation to Informal Caregivers by Health Workers	
Yes	73 (73%)
No	26 (26%)
Partially	1 (1%)
Understood explanation (if given)	72 (72%)

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Table 4. Biggest Challenges Facing Informal Caregivers

	N = 100
Inadequate bedding and seating	24 (24%)
Lack of sanitation, heat, clean running water, mosquito nets	25 (25%)
Too expensive	19 (19%)
Long wait times for care and lack of medication in pharmacy	15 (15%)
Disrespectful treatment by custodians and gatekeepers	10 (10%)
No challenges	8 (8%)
Lack of privacy and infection control	5 (5%)
Mistreatment by doctors and health workers	4 (4%)
Expensive and subpar food	2 (2%)
Segregation	1 (1%)
Language barrier	1 (1%)

questions regarding the patient. Those who were uncomfortable expressed obstacles including fearing the doctor, feeling the doctor was unapproachable, and being unable to understand the medical terminology.

Eighteen percent of informal caregivers reported that the doctor treated the patient very well, 65% well, 14% moderately well, and 3% badly. Nineteen percent of caregivers reported being treated very well, 64% well, 15% moderately, and 2% badly.

About a quarter (26%) of informal caregivers viewed their role as caretaker as not difficult, 12% as a little difficult, 44% as somewhat difficult, and 18% as very difficult. On the other hand only 13% of informal caregivers felt the medical services were very good, 61% felt they were good, 21% moderate, 4% bad, and 1% very bad.

Open-Ended Responses. The survey tool contains open-ended questions with respect to caregiver's challenges and their recommendations in terms of addressing these challenges. Table 4 shows a summary of their comments.

Informal caregivers expressed a variety of challenges. Lack of sanitation, mosquito nets, infection control, and heat were reported as challenges for both patient and informal caregivers. Lack of bedding and seating were reported as pressing difficulties specifically for informal caregivers. Lack of toilet facility sanitation was voiced as a crucial concern, as well as the close proximity of facilities to the beds and the sharing of patient facilities. The large number of beds packed close together without curtains for partition inhibits privacy and infectious control, which is compounded by the admission of patients with a variety of conditions to the wards. Insufficient funds to care for the patient and purchase prescribed medication constitute common challenges, as well as limited access to health workers and to prescribed medication due to pharmacy understock.

The deficit of health workers and the multitude of patients often results in delayed care, especially during nights and weekends when the hospital is less staffed. Pharmacy understock causes informal caregivers to venture out of the hospital in search of medication. Some medical tests are not available at the hospital, and the results of those that are available are often associated with long wait times. These tests are also very expensive, exacerbating the financial burden.

Some health workers and custodians, hospital employees responsible for cleaning the hospital, are neither patient with nor respectful toward patients and caretakers. Informal caregivers reported the gatekeepers, hospital employees responsible for controlling the movement of people into and out of the wards, as inconsiderate and disturbing and as preventing caretakers from attending to their patients.

Thoughts by Informal Caregivers Regarding Informal Caregiver Practice. The feedback from informal caregivers regarding the hospital's informal caregiver practice is summarized in Table 5.

Ninety-nine percent of informal caregivers believed the hospital policy that patients be accompanied by a caregiver is a good one. Eighty-four percent stressed the importance of full-time company of a family member for the patient to provide immediate care, encouragement, love, comfort, and emotional support. They believed that patients prefer to be cared for by a familiar person, which in turn enables family members to be constantly informed about the patient's condition. Eighteen percent stated that their role as caregiver is advantageous to staff by easing the burden of patient care for hospital staff; 5% believed they were helpful in translating conversations between patient and health worker

Table 5. Informal Caregivers' Thoughts Regarding Informal Caregiver Practice

	N = 100
Good practice	99 (99%)
Providing full-time company of a family member	84 (64%)
Easing burden of patient care for hospital	18 (18%)
Translating	5 (5%)
Bad practice	1 (1%)

in the case of a language barrier. The one informal caregiver who believed the informal caregiver policy was a bad one expressed that the hospital is already congested and in need of more nurses instead of informal caregivers.

DISCUSSION

The results of this study reveal a plethora of systematic challenges affecting informal caregivers, from the physical and practical, which cause discomfort, to the deeper and psychological, which induce indignation. Unsanitary conditions; overcrowding; lack of privacy, accommodation, and mosquito nets; and infection control comprise a multitude of challenges. Lack of medication burdens caretakers who have to search for medication, where it is often higher in cost and less reliable, as an estimated 37% of retail markets in Uganda sell counterfeit drugs.[16] Long wait times for test results delay treatment and add further stress, as does delayed treatment.

An incomplete understanding of the patient's condition and treatment can exacerbate anxiety for informal caregivers and potentially affect the care they give patients. More than one-quarter of informal caregivers did not receive an explanation from the doctor about the patient's situation, and more than one-quarter of those who did receive an explanation did not understand what was discussed. Some attendants reported fearing the doctor and being unable to understand the medical terminology. It is crucial that informal caregivers feel comfortable asking the doctor questions and be informed about the patient's condition.

In the backdrop of stresses within the hospital is the stress of informal caregivers' lives outside the hospital that they have left behind in order to care for their loved one. Almost three-quarters of informal caregivers felt that their time in the hospital affected their work or school. Some had to put jobs, businesses, and school completely on hold. The majority felt that their families were also affected by a lack of financial support or physical presence, leaving behind 4 children at home on average. Some had to withdraw their children from school, because of lack of either supervision or financial support, which is drained by the cost of hospital care. Reacclimatization to life outside the hospital when the role of caregiver expires is often difficult, particularly because of the financial burden. Ten percent of informal caregivers reported that their family missed their presence at home; however, the survey tool did not cover how the families manage in these circumstances.

The cost of care is exigent despite free hospital admission. Costs include transportation, food, medication, medical tests, surgeries, and other treatments. On average, transportation costs and out-of-pocket patient-related and personal expenses totaled 299,620 UG Shillings ($96.79 USD), whereas the average national annual income, which is inaccessible for many informal caregivers who have to leave work, is only $550, <$2 USD per day.[14] These costs are often covered by borrowed money or donations from friends and the community.

Further in the backdrop of these stresses stirs another hardship: a lack of respect from hospital employees and standing in the hospital. The consequences of everything informal caregivers give up added to the anxiety produced by the illness of their loved one is not fully understood. Additionally, in spite of the great sacrifices informal caregivers make, the full value of their contribution to patient care and hospital function has not been appropriately validated or studied. Without a means of identification, they blend in as just another person taking up space in an already congested environment. Informal caregivers deserve to take care of their loved ones in a more forgiving environment that addresses their challenges and recognizes their contributions.

Based on the study results, a series of recommendations have emerged from our team (Table 6):

The sanitation of the hospital should be prioritized by hospital management and WHO sanitation guidelines[17] followed. Overcrowding and understaffing in hospitals are known to result in inadequate infection control practices,[18] rendering hospital-acquired infections common in hospitals in the Global South. Having and meeting standards for water and sanitation are core components of infection prevention.[18] Additionally, hospital personnel may consider raising awareness about proper sanitation practices. Hospitals and health centers are ideal settings in which to establish health education programs because ill patients and their caretakers are likely to prioritize health, and sanitation is crucial in a health care setting.[17] Signs can be posted around the premises to raise awareness of proper sanitation, and health professionals may stress the point to informal caregivers during their visits. Because informal caregivers spend more time with ill patients than any other hospital staff, they are at higher risk of becoming ill themselves.[19] Blankets, mosquito nets, and curtains should be provided to all who stay at the hospital. Blankets are

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Table 6. Stated Challenges and Correlating Recommendations

Challenges	Recommendations
Explanation of patient condition not understood when given (27%) Explanation of patient condition not given to caregiver (26%)	Ensure patient's condition and treatment are fully explained to the informal caregiver using terms they understand
Lack of sanitation, heat, clean running water, and mosquito nets (25%)	Prioritize hospital sanitation and follow WHO sanitation guidelines[17] Post signs around the hospital premise to raise awareness of proper sanitation Emphasize sanitation to informal caregivers during visits by health professionals
Inadequate bedding and seating (24%)	Provide blankets and mosquito nets for all who stay at the hospital For further preventive measure, under certain circumstances, patients should be cohorted
Borrowed money to cover travel expenses (23%)	Provide transportation to the hospital at a discount for those who cannot afford it, and/or the hospital provide its own transportation between common origins and the hospital
Too high cost (19%)	Make supplemental health insurance widely available Provide affordable diagnostic modalities
Limited access to healthcare workers/long wait times for care (15%)	Ensure that workers are paid in a timely fashion, encouraged to take ownership of their work, provided needed supplies to do their work, given higher salaries or other incentives to encourage avid patient care, and take pride in their treatment of informal caregivers and other patient relatives Institute a protocol mandating that staff, prior to leaving the hospital, inform informal caregivers of what their patient needs for the remainder of that time Provide a free and optional informal caregiver training program with an emphasis on drug administration, sanitation, and basic nursing care Provide a sufficient number of health workers to be available at all times, especially on nights, weekends, and during medical student examinations
Limited access to prescribed medication due to understock (15%)	Keep the pharmacy open for longer hours and keep stock of all drugs prescribed by Mulago doctors.
Long wait times for care (15%)	Provide adequate diagnostic modalities with timely results
Disrespectful treatment by custodians and gatekeepers (10%)	Provide informal caregivers with identifying name tags
Lack of privacy and infection control (5%)	Provide curtains or partitions for all who stay at the hospital
Mistreatment by doctors and health workers (4%)	Train workers in professionalism, punctuality, dedication, empathy, and patient and informal caregiver advocacy Increase awareness of informal caregiver contributions through discussions at hospital meetings
Expensive/underpar food (2%)	Institute a program to financially assist those who cannot afford food at the hospital cafeteria
Language barrier (1%)	Use translation programs when language barriers exist
Segregation (1%)	Provide televisions, radios, and newspapers in public areas

important for comfort and warmth. Mosquito nets are pertinent to malaria prevention and are therefore necessary in the hospital because there are a high number of malaria cases in Uganda each year.[20] Curtains are crucial for privacy and infection control. For further preventive measure, wards should be organized by disease condition.

A sufficient number of health workers should be available at all times, especially on nights and weekends when the hospital is particularly understaffed. To ensure the best quality care for patients and optimal comfort for informal caregivers when hospital staff is unavailable, a protocol may be instituted mandating that staff, before leaving the hospital, inform informal caregivers of what their patient needs for the remainder of that time. The hospital may consider providing a free and optional informal caregiver training program with an emphasis on drug administration, sanitation, and basic nursing care to help informal caregivers feel more prepared for their responsibilities. Health care workers may be paid higher salaries or given other incentives to encourage them to avidly provide patient care and to take pride in their treatment of informal caregivers and other patient relatives.

The pharmacy should be open for longer hours and should keep stock of all drugs prescribed by Mulago doctors, for the benefit of both patients who need the drugs and informal caregivers who obtain and administer them.

Health workers and informal caregivers work in partnership. To help establish this respectful relationship, the hospital may consider training workers in professionalism, punctuality, dedication, empathy, and patient and informal caregiver advocacy. This training would promote collaboration with informal caregivers to maximize patient care and minimize caretaker's psychological burdens. Informal caregivers are greatly

affected by the condition and treatment of their loved ones. In this way, patient and informal caregiver advocacy are closely linked, and recognition of this relationship would be of benefit to the hospital.

Adequate test machines should be available in the hospital to reduce waiting time, thereby expediting any necessary treatment. A reduction in the costs of medical tests would help ease the financial burden and may be achieved via a partnership between the hospital and organizations that can help patients and caretakers with treatment expenses.

Informal caregivers should be provided with identifying name tags to ease hospital entry and help informal caregivers gain respect and standing. This end can be propagated by increasing awareness of informal caregiver contributions through discussions at hospital meetings.

Health care workers should fully explain the patient's condition to the informal caregiver, to create a dynamic that allows informal caregivers to feel comfortable asking questions and to ensure that communication has taken place.

It is also recommended that transportation be provided to the hospital at a discount for those who cannot afford it and/or for the hospital to provide its own transportation between common origins and the hospital; for a program to be instituted to financially assist those who cannot afford food at the hospital cafeteria; translation programs to be used by hospital staff in the case of a language barrier to enhance communication and treatment; and televisions, radios, and newspapers to be made available in public areas.

This study provided the basis to request that the hospital provide the necessary support and funding for informal caregivers, particularly because their well-being directly impacts the quality of patient care, which is the hospital's direct responsibility. Toward this goal, these results and recommendations have been shared with the management of Mulago Hospital.

Limitations. Because only informal caregivers of patients with beds in Mulago medical wards were included in this study, the experiences of informal caregivers of patients sleeping on the floor are omitted. However, the prompt transfer of patients to beds renders it unlikely that this omission greatly affected the results. The study is also limited in that it only surveyed informal caregivers in the internal medicine ward, because challenges may differ in various wards. Additionally, the results of this study may differ if conducted in hospitals and health clinics in rural areas of Uganda as opposed to the urban setting in which Mulago Hospital is located.

CONCLUSIONS

This study strongly supports the recommendation that informal caregivers be given the same respect as other hospital employees and their role be recognized as a crucial component of patient care. Informal caregivers make great sacrifices for their loved ones. They put aside their lives—families, children, school, and careers included—to care for their loved ones. They risk their own comfort and well-being, tending to their loved one's needs before their own with consequences that may endure beyond the patient's admission. Each family member feels the toll, whether emotionally, financially, timewise, academically, or otherwise, as the family unit rearranges itself to provide their loved one with the best possible care. The sacrifices informal caregivers make for their loved ones is truly admirable and should be not only recognized but lauded. Rather than increasing their burdens and anxieties, everything possible should be done to ease those burdens and, in turn, enhance patient care.

Informal caregivers spend as much time at the hospital as any other employee, if not more, and deserve to be treated with equal respect. In fact, they exhibit a dedication and empathy that may serve as a model for patient care. Through their example, other health workers can learn to give each patient the quality of care they would want for their own family members. Furthermore, their presence recreates the comfort of home care in the hospital environment so that patients are surrounded by their loved ones throughout their illness and do not suffer alone in an unfamiliar environment. With the true informal caregiver contribution known, a new model for patient care and advocacy can be established: the comfort of family care with the convenience of hospital care, without the requisite that informal caregivers sacrifice their own welfare.

As the structural pillars of hospital function, informal caregivers should be given full recognition for their invaluable contribution to patient care. To be true patient advocates, we must advocate for the greatest of patient advocates.

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REFERENCES

1. Skilled Health Workers Per 10,000 People [Chart]. (2013). In World Health Organization. BDG Asia. Retrieved June 1, 2016, from http://www.bdg-asia.com/wp-content/uploads/2014/08/2-Global-Skilled-Workforce.jpg
2. Atuhaire P. Mulago Hospital struggles to handle patient-care on its own. Kampala: Uganda Radio Network. Available at: http://ugandaradionetwork.com.dedi3883.your-server.de/a/story.php?s=46695; 2012. Accessed August 15, 2015.
3. Donelan K, Hill C, Hoffman C, et al. Challenged to care: informal caregivers in a changing health system. Health Affairs 2002;21:222–31.
4. Mulago National Referral Hospital. Available at: health.go.ug/content/mulago-national-referral-hospital. Accessed September 14, 2016.
5. College profile. Mulago Hill, Uganda: Makere University College of Health Sciences. Available at: http://chs.mak.ac.ug/content/college-profile. Accessed September 1, 2015.
6. Obore C. Time bomb: the inside story of Mulago Hospital's troubles. Daily Monitor. Available at: http://www.monitor.co.ug/News/National/Time-bomb-The-inside-story-of-Mulago-hospital-s-troubles/-/688334/1669688/-/13xumh5/-/index.html; 2013. Accessed March 1, 2015.
7. Natukunda A. Nursing Mulago's staff shortage. The Independent. Available at: http://www.independent.co.ug/news/news-analysis/5302-nursing-mulagos-staff-shortage; 2012. Accessed March 1, 2015.
8. Informal caregiving: compassion in action. Washington, DC: U.S. Department of Health & Human Services. Available at: http://aspe.hhs.gov/daltcp/reports/carebro2.pdf; 1998. Accessed August 15, 2015.
9. Feinberg L, Reinhard SC, Houser A, Choula R. Valuing the invaluable: 2011 update the growing contributions and costs of family caregiving. AARP Public Policy Institute. Available at: http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf. Accessed August 15, 2015.
10. Olai L, Borgquist L. Life situations and the care burden for stroke patients and their informal caregivers in a prospective cohort study. Ups J Med Sci 2015;120:290–8.
11. Te Boekhorstab S, Pot A, Depla M, Smit D, De Lange J, Eefsting J. Group living homes for older people with dementia: the effects on psychological distress of informal caregivers. Aging Mental Health 2008;2:761–8.
12. Buchanan R, Huang C. Health-related quality of life among informal caregivers assisting people with multiple sclerosis. Disabil Rehabil 2011;33:113–21.
13. Riemsma R, Taal E, Rasker J, et al. The burden of care for informal caregivers of patients with rheumatoid arthritis. Psychol Health 1999;14:773–94.
14. Kipp W, Tindyebwa D, Rubaale T, Karamagi E, Bajenja E. Family caregivers in rural Uganda: the hidden reality. Health Care Women Int 2007;28:856–71.
15. Uganda: World Development Indicators. Washington, DC: World Bank. Available at: http://data.worldbank.org/country/uganda; 2015. Accessed August 15, 2015.
16. Bagheri Nejad S, Allegranzi B, Syed S, Ellis B, Pittet D. Health-care-associated infection in Africa: a systematic review. Bull World Health Organ 2011;89:701–76.
17. Sanitation in hospitals and health centres: Fact Sheet 3.15. Water, Sanitation, and Health. Geneva: World Health Organization. Available at: http://www.who.int/water_sanitation_health/hygiene/emergencies/fs3_15.pdf; 2015. Accessed August 15, 2015.
18. Jörkman-Nyqvist M, Svensson J, Yanagizawa-Drott D. The market for (fake) antimalarial medicine: evidence from Uganda. Poverty Action Lab. Cambridge, MA: Poverty Action Lab. Available at: http://www.povertyactionlab.org/publication/market-fake-antimalarial-medicine-evidence-uganda; 2013. Accessed March 8 2015.
19. Kanyerere H, Salaniponi F. Tuberculosis in health care workers in a central hospital in Malawi. Int J Tuber Lung Dis 2003;7:489–92.
20. Country profiles: Uganda. World Malaria Report 2014. Geneva: World Health Organization. Available at: http://www.who.int/malaria/publications/country-profiles/profile_uga_en.pdf; 2014. Accessed August 15, 2015.