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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