Utilization of family members to provide hospital care in Malawi: the role of hospital guardians

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Abstract

Aim

Like most of sub-Saharan Africa, Malawi suffers from a paucity of human resources in the health sector. With an average of one physician for every 50,000 persons, and a health care professional to in-patient population ratio of 1:277, patient care suffers. At Kamuzu Central Hospital (KCH) of Lilongwe, Malawi, family members, termed Hospital Guardians, are utilized to provide basic care for patients. The aim of our study is to characterize this population and explore their role in the health care system of KCH.

Methods

Seventy three semi-qualitative surveys and nineteen in-depth interviews were conducted with hospital administrators, Guardians, nurses, and physicians from these wards. The results were analyzed using descriptive analysis and emergent coding.

Results

It was found that Hospital Guardians were primarily female family members of patients and have a low literacy rate. They performed a wide range of daily tasks in patient care from wound care to advocacy. Despite their essential role in the health care system, the Guardians were provided with little support from the hospital. There was often conflict between the Guardians and hospital personnel due to overcrowding with more than one Guardian per patient; a lack of understanding of hospital rules and regulations; and a lack of respect for the Guardian role by hospital staff.

Conclusions

Until their role can be reduced by additional trained health care professionals, patient care could be improved by institutional support including a clarification of the role of the Hospital Guardians. Recommendations include a one-patient one-guardian policy; Guardian education; and enhancing Guardian resources.

Background

Lack of human resources in the health care sector has led to a crisis in many countries in sub-Saharan Africa[1]. This crisis is due to insufficient nursing and medical schools, low pay and poor working conditions, the ability of trained professionals to emigrate once they complete their degrees, death due to HIV and other endemic diseases, and increased patient burden[1]. Malawi is a country of 15.5 million people with an annual GDP of $357 USD[2]. The average annual health care expenditure by the Malawian government is $31 USD per person per year[3]. An estimated 64%-77% of available health care positions in Malawi remain unfilled[1]. As of 2008, the health care provider to patient ratio was 1:2771 and the physician to patient ratio is 1:50,000[4]. With this shortage of nurses, physicians, and clinical officers, hospitals are severely understaffed and ill-equipped to provide adequate patient care.

Kamuzu Central Hospital (KCH) in Lilongwe, Malawi is a Ministry of Health referral hospital that serves a catchment area of over 4 million persons living in the central region. The hospital has 46,544 in-patient admissions per year and includes medicine, pediatric, general surgery, and obstetrical services including an intensive care unit. The burden of disease is high with HIV, TB and malaria at endemic levels and admission rates for malaria increasing by over two-fold during the rainy season. The hospital was built to house 500 patients and now regularly holds twice that. Adequate supervision and supportive care of patients is impossible without the help of the Hospital Guardians: family members, who live at the hospital for the duration of their patient's stay. They provide services that include feeding, bodily maintenance, monitoring of medications, and advocacy. Previous work in Malawi demonstrated that Guardian participation is helpful in the treatment of TB patients[5-8] and in the antiretroviral therapy (ART) program for HIV/AIDS[9]. Among HIV positive patients who receive assistance in the management of their therapy from Guardians, high ART adherence rates are a clear indication of the success of this care strategy[9].

Guardians with unspecified roles, such as those in the hospital wards, remain unstudied. While much research has been done on the varied methods of care for patients with HIV/AIDS, little focus has been put on family and community caregivers for patients with other diseases[10-12]. While the literature is scarce and not uniform in its focus, a common theme appears to be that family and community involvement in healthcare is widespread in sub-Saharan Africa[13]. We conducted the current study to expand the knowledge about the role of Guardians in the Malawian health care system. We provide demographic information and qualitative data on Guardians' perceptions of their role, and the opinions of nurses, clinical officers, and hospital administrators on the roles and importance of the Guardians at the hospital level.

Methods

Study Sites

The study was conducted at KCH from June-July 2005.

Recruitment and enrollment

Recruitment of 79 study participants took place on the male medicine (55 total beds arranged in blocks of 15 beds), labor and delivery (40 total beds arranged in blocks of 20 beds), pediatric (162 total beds arranged in blocks of 8 beds in three hospital wings), and ophthalmology in-patient wards (84 total beds arranged in blocks of 40 beds). The Guardian associated with every fifth patient bed in each ward was recruited by a Malawian study nurse trained in community practice and qualitative interviews. If more than one Guardian was present at a chosen bed, the self-identified primary guardian was acknowledged and interviewed. If a Guardian at a given bed was unavailable or did not wish to participate, the next bed was approached, and then every fifth bed thereafter. The first fifteen Guardians enrolled per ward were administered a quantitative survey. Guardians, recruited from the 16th and 17th beds, were administered in-depth qualitative interviews. The Guardian participants received a small stipend of food and soap for their time. The nurse matron of each ward chose one available nurse

and the physician on duty from her ward for interviews on the last day of investigation on that ward. Interviews were conducted with the nurse matron, the hospital administrator, and the hospital director. All participants provided informed consent. Before the study was initiated, ethical approval was obtained from the Institutional Review Boards at the University of North Carolina at Chapel Hill and the Health Sciences Research Committee in Malawi.

Surveys and Interviews

All surveys and in-depth interviews were administered by the primary investigator and study nurse in a private space away from hospital personnel and other Guardians, but still within the given ward. Qualitative interviews were tape recorded for transcription, translation, and analysis. All study case report forms were originally written in English, then translated into Chichewa by the study nurse, and back-translated by a third party for quality assurance. All qualitative interview transcripts, originally conducted in Chichewa for the Guardians, were translated into English for analysis.

The semi-quantitative questionnaire was administered in Chichewa. The questionnaire included demographic and social questions about the Guardian and their relationship with their patient, as well as travel information including distance and mode of travel, and length of stay at hospital. This questionnaire also included basic open-ended questions to obtain information about the Guardian's feelings about the hospital, the care provided, and relationships with hospital personnel. Trends were identified and summarised.

The study nurse administered in-depth qualitative interviews with two Guardians per ward as well as one nurse and one clinical officer from each ward. The questions in the qualitative interviews were open-ended regarding the roles and challenges of the participant within the health care system of the hospital, as well as the attitudes and perceptions of the care-giving groups towards one another.

Data analysis

Data from the semi-quantitative questionnaires was categorically coded. Descriptive analysis of means or medians and proportions were computed to characterise the ward, age, sex, and literacy. Analysis of the in-depth interviews was conducted using emergent coding to identifying recurring themes. Some representative examples are reported, while other trends were quantified based on analysis of in-depth interviews.

Fifteen Guardians, from each of the four wards, were given semi-quantitative surveys. No Guardians refused interviews. Two participants had been in the hospital much longer than other participant (714 days and 61 days), were considered outliers, and excluded from analysis.

Results

Demographics

The Hospital Guardians were all relatives of their patients (Figure 1). Over 80% of the Guardians were women with a median age of 37.8 years; 95% considered themselves "self-employed", many as rural farmers (Table 1). Illiteracy, determined by their inability to sign their name in the consent process, was common (72%). Only Guardians under the age of 40 were able to sign their name increasing from 21% in those aged 31-40 to greater than 60% in younger guardians (Figure 2). The median distance from their home to KCH was 48.8 Km. Many Guardians overstayed at the hospital, spending much longer than anticipated at admission (Figure 3).

Table 1: Guardian demographic data

	Pediatrics Ward	Male Medical Ward	Obstetrics Ward	Ophthalmology Ward	Total
	N=15	N=15	N=15	N=15	N=60
Female	14 (93%)	11 (73%)	15 (100%)	10 (67%)	50 (83%)
Age (median years, range)	28 (15-50)	37 (18-63)	48 (24-60)	38 (25-60)	37.8 (15-63)
Illiteracy	9 (60%)	10 (67%)	12 (80%)	12 (80%)	43 (72%)
Employment					
Self Employed	15 (100%)	13 (87%)	15 (100%)	14 (93%)	57 (95%)
Salaried	0	2 (13%)	0	1 (7%)	3 (5%)
Farmer	8 (53%)	8 (53%)	10 (67%)	12 (80%)	38 (63%)
Business	0	4 (27%)	3 (20%)	2 (13%)	9 (15%)
Housework	7 (47%)	2 (13%)	5 (33%)	4 (27%)	18 (30%)
Other	1 (7%)	2 (13%)	0	1 (7%)	4 (7%)
Distance from home to KCH (median km, range)	60 (30-700)	20 (3-200)	15 (10-50)	100 (10-300)	48.8 (3-700)

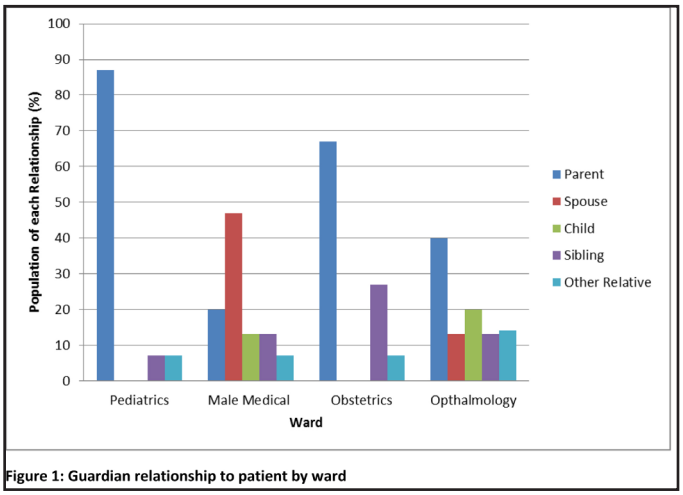

Figure 1: Guardian relationship to patient by ward

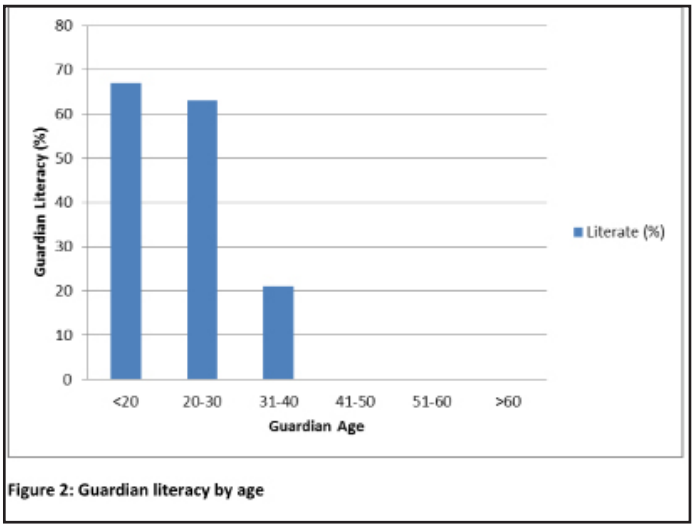

Figure 2: Guardian literacy by age

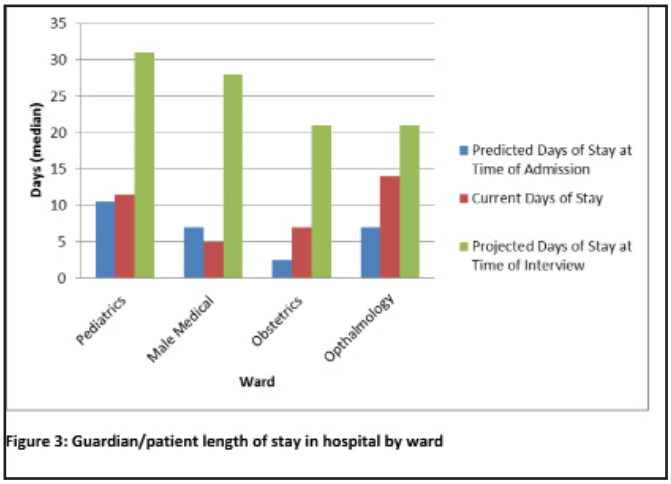

Figure 3: Guardian/patient length of stay in hospital by ward

Role of Guardians in Hospital

Guardians complete a variety of tasks in the wards. All Guardians mentioned the need to cook for and wash their patients daily. They felt it necessary to be present to assist with medications, wound cleaning and dressing, and the emptying of bedpans. Their daily tasks also included laundry, taking care of additional children, small jobs around the hospital to earn additional money, and helping other Guardians with whatever they might need. Guardians all spoke of their role as advocates for their patients, saying: "observing the patient, whether the patient is improving or not, and reporting to the doctors". With the nursing shortage the Guardians felt it necessary to be a constant presence by the side of their patient. Guardians claimed that without this diligence, patients may go unobserved for large portions of a day, or many days: "I cannot leave him; this is why sometimes I don't eat. I want to be close to him and monitor his condition".

Support for guardians

Guardians complained of a shortage of basic necessities needed for them to live comfortably. They mentioned lack of space and a place to stay, money, food, firewood, and other supplies as daily difficulties. A wife acting as Guardian in the medical ward said:

"I have over-stayed in the hospital, and my home is very far; the money I had has finished. Even myself to find food to eat is a problem"

A sister acting as Guardian to her brother who was being treated in the ophthalmology ward said:

"I fetch the firewood behind the hospital where they cut down trees, where they are clearing the ground. We sell maybe ten or twenty Kwacha to keep us going"

Without a safe place to sleep at night on the hospital campus, Guardians mostly slept in the wards, next to the beds of their patients. While a Guardian shelter did exist on the hospital grounds, the Guardians were locked out due to power outages and misuse by Guardians and other hospital visitors. The Guardians used the shelter yard for cooking and washing, but they did not feel that it was a safe place for them to stay or to leave their belongings while they were in the wards.

Impact of Guardian absence on home village and family

Guardians spoke of the stress that being a Guardian put on their family back home. Many Guardians brought additional young children with them to the hospital. They were often breast feeding the child and had no one else to take the child or replace them as Guardian. Guardians surveyed had an average of four children remaining at home in the care of a relative. They noted that dry season months were the best time to be a Guardian as it did not interfere with the planting and harvesting of crops. For those Guardians who were not farmers, the loss of someone managing a family store, or the loss of a job was often of critical concern.

Relations with hospital staff

When Guardians were asked about relations with hospital personnel, they were often grateful for the treatment given to their patient, but followed this praise with concerns about the lack of time and energy the nurses had for their patient. It was important to all Guardians that the nurses care personally for their patient. A 28 year-old mother said:

"They should be polite to our patients, be humble and show love to our patients in so doing our relationship will improve"

They worried that if the Guardian were absent, no nurse would check on their patient, even to provide medications. A 39 year-old wife caring for her husband in the male medical ward said:

"If they say we are busy, we will attend to you later, we should hold on, they should remember to come and attend to us, and not 'we shall attend to you later,' meaning they will not come to attend to you."

Guardians were at times asked to leave the wards for cleaning or for reasons of overcrowding. Many Guardians expressed worry about what negative effect their absence could have for their patient's wellbeing. A 48 woman caring for her post-partum sister-in-law in the obstetrics ward said:

"They chase use out like, 'Go out, you're behaving as is the hospital is your home.'"

Guardians felt that they were such an integral part of their patient's care that they should never be asked to leave the side of their patient. They felt they should be included in discussion of treatment and treated as an important part of their patient's recovery process. Many admitted that they did not have a full understanding of their patient's illness, the hospital system, the official visiting hours, or the methods used by the nurses to make sure that all patients were seen. The Guardians mentioned poor communication as a source for much disagreement between themselves and hospital personnel. They wished that nurses would take more time to speak with them about their patient's condition and about hospital policies so they could understand what was going on with their patient, and for this, be better caregivers themselves. The Guardians would not ask questions "because we are afraid to do so."

Hospital Personnel's Opinions of Guardians:

Nurses and physician were unanimous in their feeling that Guardians were a necessary part of the KCH health care system, stating, *"Those Guardians are like eyes for the nurses"*. The nurses felt that with the shortage of health care providers, Guardians played an important role in the well-being of the patients, for daily maintenance, and as patient advocates. That said, all of the hospital personnel interviewed agreed that the best solution to any problems occurring in relation to the Guardians would be to eliminate the hospital's dependence on this population. A medical officer in the medical ward said:

"Ideally if we have a good number of nurses, then they [the Guardians] could not have been very important, but as of now, we have a critical

shortage of nurses so I still feel that the place of the Guardians is important"

Both nurses and physicians mentioned access to patients being difficult due to the overcrowding of Guardians in the wards. They also complained of a lack of Guardian knowledge about hospital procedures and facilities. Examples of nurses' complaints about Guardians include: unwillingness to leave when visiting times were over; misuse of hospital sinks and toilets; and improper use of health care appliances, such as gloves and bedpans, were. A nurse in the ophthalmology ward said:

"Like we say 'can you please go out, this is our time, we want to care for the patient', and the Guardians immediately say, 'I can't go out because my patient is very sick and I am supposed to be here; how are you going to care for the patient?"

They wished Guardians knew more about infection control and basic health care skills. They claimed Guardians couldn't understand their directions. Some even claimed that the Guardians weren't listening.

Hospital Administration

Three members of the hospital administration were interviewed. The head nurse matron and the hospital director represented the two most contrasting opinions on the Guardians. The head nurse matron believed that guardians played an integral role in the wards of KCH.

"I would think that the Guardians are really part of us. They are playing a role… I think they are like a hand indeed"

She believed that while the notion of hiring more nurses to alleviate the burden of the Guardians was a nice idea, a realistic approach needed to be taken when addressing the challenges of the Guardians and their role in the hospital's care of patients. She agreed that crowding was a major issue in the wards and that some steps should be taken to address this issue.

"So maybe, we would indeed have some education where they would really understand and appreciate why we are saying that not all of them should be in the ward because in our hospital we have a big problem with overcrowding"

She also believed that better communication, education, and support of Guardians would be helpful for improving their role in the hospital.

In contrast, the hospital director was steadfast in his belief that improving Guardian relations was not a good way to improve patient care. His aim was only to hire more nurses in order to eliminate the need for Guardians in the hospital.

"They are disruptive to the system. They put a lot of stress to the facilities that we have because roughly we have three Guardians to a patient… "

The hospital director realized that eliminating the Guardians all together was an impossible goal due to their cultural role in Malawian health care and the current nursing shortage, but given the chance, he would reduce the role of Guardians at the hospital to that of merely visitors, not members of the health care team.

The principle hospital administrator believed that one way to improve hospital function in regards to the Guardian would be,

"to restrict the number of Guardians that are visiting the patient. Second, maybe there is need to give them some civic education. For the people who are spoiling our toilets. Toilets get broke now and again because of the over-crowding so we need to give some civic education… I think basically we should target health education and what hygiene the hospital is expecting them to do. What care they are supposed to take care of themselves so that they don't get infected".

Discussion

Guardians played an essential role in the in-patient healthcare system in Malawi, primarily due to the nursing and physician shortage. Each nurse cared for 30-80 patients per shift, and for this, tasks were shifted to Guardians. We identified three key issues facing the hospital and the Guardians, including the financial impact on the Guardians and their families back home, poor communication, and crowding in the hospital.

The Hospital Guardians of KCH were predominantly female as it was seen as disruptive to a family's livelihood and economic status for a man to leave the household for long periods of time. Simultaneously, Guardians, many of whom were farmers, were often faced with the reality of failing to provide for the family they left at home including their children. This problem was compounded as Guardians underestimated the length of time they would be away from their home villages due to a poor understanding of the severity of the illness at the time of leaving the village. The Guardians with long hospital stays noted similar barriers as Guardians at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi, who were helping with pediatric patients with Burkitt's lymphoma and Wilm's Tumor[14-15]. As at KCH, the Guardians at QECH noted a lack of support and supplies, which were major hindrances to their ability to stay for the duration of a long chemotherapy treatment.

Poor communication between the hospital staff and the Guardians and unclear expectations often hindered the effective participation of Guardians in care-giving roles. With the enrollment rate in secondary school in Malawi at 27.5% in 2010[16], over 70% of Guardian participants were illiterate, which made their ability to understand communications from the nurses problematic. There is a dearth of existing literature outlining the feelings of nurses, physicians, and hospital administrators on the roles and importance of the Guardians at the hospital. Previous literature on Guardian populations in southeast Africa focused on their specific roles in the treatment of particular diseases such as tuberculosis and HIV[5-8], on the Guardians role in the delayed presentation of patients to the hospital[15], and the reasons for patient leaving care[14, 17]. Our study provided details of the Guardian's opinion about hospital personnel and their treatment of patients. As at KCH, the Guardians at QECH also felt that they had trouble communicating with hospital personnel.

Poor communication led to mistrust.

Guardians feared their patient being missed or ignored by hospital staff too busy to notice a quiet patient, a patient who is not in bed at the time of rounds, or a patient who is deemed well enough to be safely overlooked during hectic rounds. This shortcoming of the hospital was not due to clinical staff not caring; it was an issue of a shortage of nurses and physicians coupled with a poor reporting system. The successful use of Guardians in the treatment of TB and HIV is an indicator that well-directed Guardian care in the hospital setting could be beneficial to in-patient care and could result in better treatment outcomes.

In our study, nurses and clinical officers realized that Guardians were a necessary part of the health care team, yet they found their overwhelming numbers and lack of

knowledge of the wards, basic patient care, and infection control to be hindrances to their work. To exacerbate the existing patient overcrowding problem, many patients had more than one Guardian, with some having as many as four or five. Overcrowding of Guardians was emphasized by the ward staff and administration as a major problem both in patient care and in the function of hospital facilities. All members of the hospital team at KCH including administration, nurses, physicians, and Guardians themselves agreed that Guardians were a crucial part of patient health. Members of the hospital administration had differing opinions on the utility of Guardians in patient care. Some were more understanding of the Guardian's situation in the hospital, while others took a more dogmatic view regarding the impact of Guardian's on the hospital system itself. However, they agreed that to utilize Guardians, to support them, educate them, and to make them a more active part of the health care team would be beneficial to patient care in a setting where the Guardians are clearly a presence in the Malawian health care system.

Recommendations:

There were a number of potential, low cost solutions to improve the utilization of Guardians in the current system. The concerns of Guardians, in addition to the concerns of staff in the wards, indicated that increased support and education of Guardians would greatly improve patient care as well as relations between health care-providers. The following recommendations were made in collaboration with the KCH administration and represent feasible and low cost solutions to some of the most pressing issues regarding the Guardian population today.

a. Create educational material for guardians to use in the wards:

Educating Guardians would alleviate the frustrations of hospital personnel and Guardians as well as benefit patient care, perhaps leading to improved patient outcomes at KCH.

b. Implement a one patient, one Guardian rule:

This policy would allow each patient to have a single advocate and point person who could be individually educated by the ward nurses regarding the care of their patient. This would empower the Guardians by giving them a more official role in the care of their patient.

c. Coordinate work around the hospital so that Guardians can earn money for food and living space

Small jobs around the hospital for which Guardians could earn some money would allow Guardians to better support themselves, their patients, and their families.

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