Compassion Versus Infection Prevention and Control in Hospital Visiting; A False Dichotomy? A Case Study of Informal Caregiving in a Ugandan Regional Referral Hospital

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Abstract

This paper addresses the role of visitors or ‘attendants’ in the transmission and management of infection risk in a public referral hospital in Uganda. The study built on research on maternal sepsis which found that over 50% of antibiotics administered in the hospital were for Healthcare Associated Infections (HAIs). The data was collected during the COVID-19 pandemic which introduced new risks and heightened concern about social movements within hospitals and between hospitals and communities. In the first study of its kind, observational data was collected on a 24/7 basis to capture the presence and roles of attendants in a low resource setting exposing both the infection risks associated with these forms of movement but also the absolute necessity of attendants in the management of infection risk in such contexts. The paper responds directly to a recent call for a ‘new conversation on infection prevention and compassion’ (Storr et al, 2023;408).

Introduction

Healthcare associated infections (HAIs) are a significant burden to health systems, capable of harming patients, visitors and healthcare workers alike. The World Health Organisation estimates out of every 100 patients in acute-care hospitals, seven patients in high-income countries and 15 patients in low- and middle-income countries will acquire at least one HAI during their hospital stay (WHO, 2022). The hospital environment plays a significant role in the development of HAIs, with various surfaces, medical devices and equipment acting as a reservoir for potential pathogens. Furthermore, there is a heightened risk of resistance developing through continuous and increased use of disinfectants and antimicrobial drugs (Cason et al, 2022). Whilst healthcare workers are frequently encouraged to follow adequate infection prevention and control (IPC) measures for the safety of themselves and the patient (Alhumaid et al, 2021), what is less clear is how attendants fit into the equation in terms of both patient outcomes and their contribution to the hospital microbiome.

Current research, much of which is focused on the COVID-19 pandemic, tends to adopt one of two binary positions. Some papers take the view that the social movements associated with hospital visiting pose a high risk in terms of infection transmission, justifying a policy emphasis on reducing the number or length of visitor stays (Hung et al, 2020). A key concern here is with health worker safety and the systems impacts of health worker illness (Backhaus et al, 2021; Hsu et al, 2020; Maurand et al, 2023). The majority of papers question this assertion arguing that there is insufficient evidence and risks can be effectively mitigated (through IPC interventions) and balanced against the negative impacts on patient, visitor and health worker well-being (Forsberg et al, 2023; Mistraletti et al, 2021; Montesante et al, 2023; Hindmarch et al, 2021; Jungestrand et al, 2022; Muniraman et al, 2020; Rose et al, 2020; Stemler et al, 2022; Wendlandt et al, 2022). A proliferation of papers concur on two issues: the huge variation in policy over time and place and major weaknesses in implementation. Even within one country, policies vary between institutions and patient groups, are in a constant state of flux and are patchily enforced (Ya-An Liua et al, 2020). While this may be understandable in a pandemic context, it poses a major problem in terms of public understanding and compliance.

Those of us that lived through the COVID-19 pandemic are only too aware of the emphasis that was placed on human mobility leading to ‘social mingling’ as a primary vector of transmission. In times of crisis and when confronting a novel infection, there’s a certain common sense to this notion. But, in the aftermath of the pandemic as researchers assess the unintended consequences of interventions, a debate has emerged describing the ‘trade-off’ between compassion and infection prevention control in the management of hospital
‘visitors’ (Hsu et al, 2020). A recent paper by Storr et al critiques this ‘false dichotomy’ and calls for a ‘new conversation on infection prevention and compassion’ (2023;408). The authors contend that ‘IPC and compassionate care are not mutually exclusive’ and articulate an urgent need for policy review to prevent policy institutionalisation and facilitate ‘de-implementation’ (p.407). Other authors make a similar case to support heightened preparedness (Backhaus et al, 2021). A minority of papers go a step further, arguing that informal carers play an important role in infection prevention. Muniraman et al’s work on hospital visiting in tertiary level neonatal units in the UK and US is a case in point. They argued that COVID-19 restrictions on visiting potentially undermined ‘a paradigm shift in the parental role in the neonatal unit; parents are no longer considered ‘just visitors’ but rather an integral and essential part of care provision’ (2020;4). The authors cite evidence that Family Integrated Care models not only contribute to the quality of care but decrease length of stay and HAIs.

Whilst COVID-19 inevitably stimulated interest in this topic, concerns around the role of social mingling and visitor movements within health and social care facilities are not new. This paper builds on research on antimicrobial stewardship in a Ugandan Regional Referral Hospital focused on maternal sepsis (Ackers et al, 2020; 2020; Ackers-Johnson, 2020). Closely aligned to the National Action Plan (NAP) on Antimicrobial Resistance (Ugandan MOH, 2022) and the emphasis on health workers as vectors of nosocomial transmission, the Maternal Sepsis Intervention (MSI) demonstrated remarkable success in health worker behaviour change. It also identified a major concern, amongst health workers, about the role of hospital visitors or ‘attendants’ as vectors of nosocomial infection. The NAP identifies the need to ‘create and promote specific guidelines for limiting the spread of multidrug resistant organisms and promote campaigns for infection control at health care facilities’ (Objective 3). There is no recognition of hospital visiting in the NAP and the role that this form of ‘social mingling’ plays in the management of infection transmission. Certainly, the flows of attendants between hospitals and communities and their circulation within facilities during patient stays presents a challenge to accepted distinctions between health care and community-acquired infection. Denyer-Willis and Chandler argue that discussions about antimicrobial stewardship have been pre-occupied with antibiotic consumption suggesting that, ‘antibiotics have become ... a quick fix for hygiene in settings with minimised resources’ (2019:1). Arguably, the same could be said of blanket restrictions on hospital visiting. An alternative approach would be to conceptualise IPC as an ‘enabler’ to informal caregiving (Storr et al, 2023:407), perhaps even seeing caregiving as an essential enabler to hygiene in hospitals.

**Visitors, Companions, Attendant, Hired Caretakers or Unpaid Health Workers?**

The identification of informal carers as active agents in infection prevention rather than simply an additional IPC risk is potentially critical. However, there is little detailed evidence of these roles and how they are enacted in practice. Who are the visitors? How long do they spend on the ward? What do they do? And how do their roles interact with the roles of formal caregivers (health workers)?

Cultural norms and local policies frequently influence the role of visitors. Montesanti et al (2023) argue that the implementation of restrictive policies in Canada supported a dominant narrative of families as visitors rather than ‘essential partners in care’ (2023:1). Conversely, in a Taiwanese study, Hung et al distinguish ‘inpatient companions’ from ‘visitors’. The role of inpatient companions, they suggest, reflects the ‘traditional filial piety culture and family structure inherent in Taiwan’ based on inter-generational and highly gendered familial
reciprocity (2020;1112). However, the differences are not always clear cut, with multiple studies also seeking to
distinguish general visitors from those facilitating key family care and support (Hindmarch et al, 2021; Forsberg
et al, 2023). Interestingly, the two studies representing low resource settings (Sultana et al, 2008 in Bangladesh
and Zulfiqar et al in Pakistan, 2013) describe those visitors who take a primary and more continuous
responsibility for patient care as ‘attendants’. This is the term commonly used in Uganda; and for the purposes
of this paper, we will refer to all visitors as attendants.

It is also worth noting different scenarios in which informal care may be given; either through the use of ‘hired
caregivers’ as paid substitutes in public hospitals (Hung et al, 2020), or ‘volunteers’ substituting for ‘relatives’ in
the form of representatives from religious organisations, users and ‘civilian volunteers’ (Maurand et al, 2023). In
each case, varying responsibilities come with their own individual IPC risk attached, which must be evaluated
when establishing guidelines.

The Attendants Study

Empirical data collection for this study took place between September and December 2020 on the public
maternity wards at Fort Portal Regional Referral Hospital, Uganda. Whilst Uganda is classified as a Low- and
Middle-Income Country (LMIC) (United Nations, 2014), there is a great diversity in health facilities, with a poorly
resourced public sector and a burgeoning private sector. Support from overseas makes up a significant share of
public sector resourcing and is often shaped by a highly medicalised global health agenda, with overall resource
allocation frequently affected by political decisions (or non-decisions) at a national and facility level (Ackers et
al, 2020). Visiting policies and behaviours will be very different in well-funded private and Non-Governmental
Facilities.

The intention to study the role of attendants was planned prior to the COVID-19 pandemic, in response to data on
the incidence of nosocomial infection and antibiotic consumption in cases of maternal sepsis. The pandemic
only accelerated our interest, providing a unique point in time where stringent IPC guidelines should have been in
place. In order to capture in-depth data on the characteristics, volume, timings and roles of attendants the team
decided to undertake intense 24/7 observational work with a sample of 30 consenting patients on the linked
post-natal and gynaecology ward. Observations were undertaken by two Ugandan midwife co-researchers
working on the ward on a supernumerary basis (for the period of data collection) and recorded in notebooks.
Where necessary, the researchers had conversations with patients and attendants to clarify relationships and the
geography and purpose of any movements on the ward, within the wider hospital and between the hospital and
community. Notes were then transcribed, anonymised and thematically coded in NVIVO. Ethical approval for the
work was granted by the University of Salford with support from the Hospital Director.[5]

Findings

The findings are presented as follows. Section 1 describes the characteristics of the attendants in terms of their
relationship with the patient they are supporting and their gender. Section 2 examines their roles and is split into
3 sub-sections distinguished by ‘movement geographies’. We first examine those movements and contacts that
take place on the ward itself. This is followed by analysis of those more frequent movements that take place
within the confines of the hospital campus, between wards and facilities. Finally, we focus on those movements
that connect the hospital to the external environment (home, town and other health facilities). When combined
with an analysis of roles a complex picture emerges identifying attendants simultaneously as potential vectors of health facility and community transmission and critical actors in IPC management. Most importantly, the level of detail supports a more balanced, evidence-based, approach to risk mitigation.

**Section 1. Attendant Relationships**

A total of 147 attendants were observed supporting 30 patients giving an average of five attendants per patient. The observations identified a range of 'Visitor-Types' (Table 1). Attendants were predominantly relatives (120 compared to 27). If we look at the ‘relatives’ category, 87 (72.5%) of the relatives attending were female and 33 (27.5%) were male. Unsurprisingly, in Ugandan tradition, sisters, mothers and aunties predominate. This echoes Zuliqar et al’s finding that, ‘nearly 90% of attendants were blood’ relatives’ (2013:144). In our sample, friends nevertheless form 18% of visitors:

<table>
<thead>
<tr>
<th>Number of that Visitor Type Attending</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister</td>
</tr>
<tr>
<td>Mother</td>
</tr>
<tr>
<td>Aunt</td>
</tr>
<tr>
<td>Mother-in-law</td>
</tr>
<tr>
<td>Sister-in Law</td>
</tr>
<tr>
<td>Daughter</td>
</tr>
<tr>
<td>Niece</td>
</tr>
<tr>
<td>Grandmother</td>
</tr>
<tr>
<td>Husband</td>
</tr>
<tr>
<td>Father</td>
</tr>
<tr>
<td>Brother</td>
</tr>
<tr>
<td>Uncle</td>
</tr>
<tr>
<td>Brother-in-law</td>
</tr>
<tr>
<td>Son-in-law</td>
</tr>
<tr>
<td>Father-in-law</td>
</tr>
<tr>
<td>Son</td>
</tr>
<tr>
<td>Cousin (female)</td>
</tr>
<tr>
<td>Pastor</td>
</tr>
<tr>
<td>Friend</td>
</tr>
</tbody>
</table>

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The Temporal Quality of Attendant Stays

The emphasis in the literature on length of visitor stays perhaps reflects the importance attached to visitor volume (as a key presumed variable in nosocomial spread) as much as any fundamental culturally-defined relationship. However, most of the research in high income settings makes an assumption that visiting takes place during the working day and focuses on the duration of stays (often one hour) and designated visiting times. Even pre-COVID-19, restricted visiting times was seen as important to protect ward rounds, mealtimes and enable the patients to rest. Where overnight stays are envisaged, particularly in neo-natal intensive care units, papers refer to the need for designated sleeping rooms (Muniraman et al, 2020). This is not the situation in public hospitals in most low-income settings. In our Ugandan sample, all patients were supported from the point of admission to departure on a 24/7 basis with most stays lasting between 48 and 72 hours (Table 2):

<table>
<thead>
<tr>
<th>Duration of Patient Visit</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 hours</td>
<td>1</td>
</tr>
<tr>
<td>24 hours</td>
<td>3</td>
</tr>
<tr>
<td>48 hours</td>
<td>14</td>
</tr>
<tr>
<td>72 hours</td>
<td>10</td>
</tr>
<tr>
<td>4 days</td>
<td>1</td>
</tr>
<tr>
<td>6 days</td>
<td>1</td>
</tr>
</tbody>
</table>

Sultana et al (2008) similarly identify ‘round-the-clock care’ in Bangladesh and 85% of Zuliqar et al’s attendants in Pakistan stayed on site ‘non-stop’ for the duration of the patient stay.

Section 2. The Geographies of Attendant Movements and Associated Roles

All patients in our sample had at least one attendant with them for the duration of their hospital stay. In practice, some attendants will spend much longer with the patient than others who may make frequent or infrequent shorter ‘visits’. This inevitably means that attendants effectively live on the hospital campus, moving between wards and outside areas to sleep, wait and undertake the daily tasks they need to look after themselves and, quite often, accompanying children and babies. With the exception of an area for cooking (using charcoal fires) and washing lines, the hospital does not provide any facilities specifically for attendants for personal washing, toileting, waiting or sitting/sleeping. After several readings of the cases, the following categories emerged as the main activities that attendants engaged in. We have grouped these according to the kinds of geographical mobilities (and associated contacts) involved. Group 1 ‘Within Ward’ captures movements and behaviours taking place on the ward. Group 2 ‘Within Hospital’ mobilities captures occasions where attendants move around the hospital campus between wards, theatres and pharmacies or to wash and cook. The final category, ‘Community’ mobilities captures those movements connecting homes and communities to the hospital.
Geographies of Care Mobilities

Within Ward Movements and Contacts

The overwhelming majority of research focuses on high income settings. While some of these papers recognise the potential link between emotional and physical well-being, in these settings most of the routine ‘hands-on’ care is provided by health workers, a stark contrast to the situation witnessed in this study. ‘Within ward’ movements encapsulate the core hands-on care responsibilities of the attendants, which result in key routes of potential infection transmission between them and the patients they care for. As described below, these activities range from low risk, for example emotional support and prayer, through to high risk, where attendants are responsible for the patients’ hygiene including changing sanitary pads and dressings. In terms of IPC, activities taking place immediately prior to and after patient contact are critical, with good hygiene practice reducing the risk of attendants transmitting infectious organisms not only to the patient, but to the wider community.

Figure 1 provides a site plan of the ward to give readers an impression of the layout. There are sufficient beds for 40 patients, and it is common to have between five and ten patients on mattresses on the floor known as ‘floor cases’. Two midwives will be on duty at any one time covering both wards. During the day these will be joined by a varying number of medical officers, intern doctors and students.

It is just as important to emphasise the commonality of experiences that patients in LMIC and HIC countries share as it is to draw out differences. Attendants in Uganda play all the roles that are identified in the published research. These more expected roles include routine social and emotional support and prayer. In one case a husband was observed to be simply, ‘sitting at the end of the bed holding the patient’s hand as she was unconscious’ [05]. Many of the observations referred to conversations taking place between attendants and patients and support to ease pain and discomfort, ‘covering the patient with a blanket as she was feeling cold’ [10], ‘rubbing her back as she was in pain’ or ‘praying for her’ [04]. In addition to these ubiquitous visitor roles, the attendants in Uganda provide comprehensive support systems that are often provided by health workers in high income settings.

Supporting the nutrition and hydration of patients and babies involves a range of repeated movements connecting the hospital with home and town and requiring on-going mobilities within the hospital grounds. It also forms a focus of highly intense social mingling on the ward itself, often extending to quite large family/friendship groups that interconnect with neighbouring patients. The following, quite typical, case involved the patient, her baby, her mother and an aunty:

[The mother] served tea to the patient as instructed by the nurse. She then supported the baby on the mother’s breast. Then the patient and the aunt sat down on the mat on the floor where the mother served food [09]

Equally, with food, once prepared and brought onto the ward it is common for the family group to sit on the floor or on the patient’s bed to eat, drink and socialise:

The patient sat on the floor with the village friend and started conversing. She told the patient to sit on the floor so as to eat together from a container [23]

These family groups are sometimes joined by children, including children of other families:
Two children of an attendant of another patient sat on their mat while eating food [05]

It was quite common for attendants to ‘sit on the slab’ whilst eating or drinking. The ‘slab’ is a raised area that forms an effective seat. However, it adjoins the high dependency area of the ward where women are in a critical condition:

He sat on the slab took tea which poured on him and cleaned himself with a cloth [03]

On the ward, attendants are involved in intense bedside activities including making and changing beds, cleaning up body fluids and assisting with toileting. No linen is provided by hospitals. Cleaners are employed in the hospital and clean the ward every morning, but they are not available on an ‘on-call’ basis and most routine patient-related cleaning is performed by attendants. This includes cleaning up vomit and blood:

After the patient vomiting, the sister cleaned the patient at the bedside [05]

[The attendant] was cleaning her as she was soiled with blood [24]

Attendants are also wholly responsible for ensuring both patients and babies are kept clean. Public hospitals do not provide disposable sanitary towels or nappies. Attendant roles include bedside washing, taking patients to the adjoining washrooms and emptying catheter bags:

The daughter was seen taking the patient to the toilets and the washroom to bathe [12]

She emptied the urine bag 3 times since the patient was operated and poured out urine [01]

The son woke up in the night by the patient to help her squat on the basin to urinate and then he poured out urine in the toilets [16]

Attendants are also responsible for changing sanitary pads and dressings:

The mother woke up in the night and changed the pad as it was soiled with blood [06]

When evaluating maternity wards, there is often a ‘2-body’ problem where both mother and baby require care. Taking care of babies, especially when many mothers cannot afford disposable nappies, involves on-going work:

The sister cleaned the baby [whilst] the friend cleaned the patient in bed [11]

When attendants are co-resident the two bodies can become many. There are no separate facilities for attendants to wash and toilet themselves, so they have to share the cramped washrooms. While Fig. 1 shows four sinks, at the time of writing only one was functional. Respondents spoke repeatedly of the poor state of hygiene in these facilities and their preference to either not wash at all or go into town or home to do so:

The attendant didn’t bathe because of the fear to get infections from the washrooms [09]
Very few of the published papers identify the kinds of roles we have seen above. One study in paediatric hospitals in Mexico City identifies roles that expose caregivers to body fluids (faeces, saliva, blood and mucus). The authors suggest that having family undertake such tasks, ‘potentially decreases the risk of infection for health personnel’ (De la Rosa-Zamboni et al 2022:6). Furthermore, the families may be ‘more careful in hand hygiene’. The authors reported that the carers responded extremely well to IPC training despite the fact that 70% of their sample were in extreme poverty with low educational levels (p.6).

One of the greatest concerns from an infection-control perspective is the sleeping arrangements for attendants. Night-time is the time when there are fewest health workers on the ward so attendants play an absolutely essential role in monitoring patients, supporting them and alerting staff should the need arise. In practice there will often be one or perhaps two midwives managing the whole area. The only furniture on the ward is patient beds. There are no chairs or space for attendants to rest. In practice attendants flood into the wards at night creating major congestion and bringing often heavily soiled mattresses. Where the opportunity arises, they will sleep on spare beds or share beds with patients or other attendants:

*He slept on bed with an attendant of a different patient because all beds were occupied with other attendants [02]*

In the next case both the husband and sister slept on the floor next to and under the patient’s bed:

*The husband went home to pick the mattress to sleep on. The sister laid a cloth on the mat which was on the floor and slept as the husband slept on the mattress he brought from home [05]*

Often sharing beds will include the new baby (no cots are provided):

*The mother-in-law slept with the patient on the same mattress on the floor with the baby in between them [17]*

*The husband laid a cloth down to sleep and his friend slept on an empty bed next to the patient. The husband came back and slept again on the patient’s bed [20]*

A number of cases have been cited here as we believe this is some of the most high-risk behaviour. Most caesarean sections occur at night when staffing levels are at their worst. In the following case the patients were instructed to also move to the floor as new patients were arriving:

*The nurse on night duty told attendants to shift the patients to the floor as the beds they were on were going to be occupied by other new patients from theatre [12]*

Zulfiqar’s paper is one of the only papers that identified issues around lack of accommodation for attendants with many of those who had travelled some distance ‘sleeping under the open sky either at the hospital or roadside’ (2013:144). We have noted the infection risks associated with this very congested form of social mingling involving not only people but also bedding and cooking items. The co-presence of attendants during the night involves some of the most critical roles both in terms of patient hygiene but also monitoring and surveillance. Montesanti et al (2023) refer to caregivers as a ‘second set of eyes and ears’ playing a critical role in patient safety and surveillance. With reference to intensive care contexts in high income settings, both Forsberg et al (2023) and Wendlandt et al (2022) identify informal caregivers as key communication brokers and ‘surrogate decision makers’ alerting health workers to the need to escalate support. In contexts where health
worker-patient ratios are very compromised attendants are on the front line. The following excerpts give an impression of the kinds of roles attendants play in monitoring medications and pain:

*The sister went to find the nurse to replace the intravenous fluid which was complete [18]*

*[She] informed the nurse on duty two times as the patient was complaining of pain [05]*

Attendants also played an important role as witnesses in consenting procedures:

*The attendant signed a consent form that was given to him by a doctor as the patient was going to be operated [02]*

These cases underline the essential role that attendants play and signal the risks associated with any attempt to restrict them.

**Infection Prevention and Protective Equipment for Attendants**

A predominant theme emerging from the literature concerns the importance of providing infection control measures and personal protective equipment (PPE) for visitors to mitigate the impacts of this form of social movement. Once again, the literature tends to report mainly on high income settings and makes an assumption that it is the responsibility (and within the budgets) of the health facilities to provide protective masks (typically N95 masks and with daily replacements); hand washing (with soap etc.), hand sanitiser, temperature monitoring and public health vaccination programs. Other papers report measures including history and contact tracing. The emphasis in many of these papers is on the efficacy of health awareness-raising in supporting visitor compliance.

In the early stages of the COVID-19 pandemic there was a great deal of cynicism about its prevalence and impact in Uganda (Loembe et al, 2020; PERC, 2020). This was reflected in little initial impetus to manage public access to health facilities. At that point the main entrance gate to the hospital was often open as were other access points. During a second phase, coinciding with data collection in this study, the gate was in theory manned and had portable hand-washing facilities (with diluted jic[6]) provided. The hospital also introduced a formal policy of 1 attendant per patient although enforcement was always a problem. Later, the post-natal ward also introduced a hand-washing station outside the entrance and, when supplies permitted, hand gel. There are no sinks for patients or attendants to use on the wards. Implementation of measures was sporadic at best. The following cases provide examples of patchy adherence both on entry to the ward and on exit to embark on journeys home:

*They neither used alcohol hand gel nor water on the ward saying that they washed their hands from the main gate as they entered the hospital [01]*

*The father, brother and [second] sister to the patient left the ward without washing their hands and went home [05]*

In the next case the respondent explains that his familiarity with the guard responsible for ensuring attendants had their temperatures monitored enabled him to avoid doing so:
On coming back on ward, he washed his hands, but his temperature was not taken because the security guard has been seeing him around the hospital [16]

Researchers also made observations about adherence to the policy of requiring everyone to wear masks. Policies on mask wearing were very difficult to enforce in Uganda as the global pressures on supply chains resulted in scarcity and price escalation. The hospital was unable to provide any PPE for visitors and patients and struggled to provide it consistently for staff. Where attendants did possess masks, they often didn’t change them regularly or wear them properly:

They sat on the bench as the nurse was admitting the patient and they didn’t have their masks on.

The grandmother and friend were not wearing masks correctly. [They] were worn under the chin [03]

**Movements within the Hospital**

It is within this context of very limited access to IPC protection and poor compliance that we turn to movements within the wider hospital complex. There is little direct reference to these forms of visitor movements in the literature beyond advocating that visitors use separate entrances. Some of the literature suggests that visitors may play less of a role in nosocomial spread within hospitals precisely because they form ‘bubbles’ with the patient and do not move around as much as health workers are required to do (Muniraman et al, 2020). The only paper that expressly refers to this form of movement is the paper discussing the substitution of family carers with ‘volunteers’ in France. Maurand et al suggested that the fact that these volunteers went from ‘room-to-room’ to visit different patients generated a risk of cross-transmission of pathogens which was less likely to occur with family carers (2023:2). Their study involved the use of a 3-hour training program leading to a ‘Infection Control Passport’ designed to reduce these risks. In the Ugandan context attendants move throughout the hospital regularly for a wide variety of purposes (and locations).

Where a patient needs to move from one clinical area to another the lack of access to hospital porters in public hospitals in Uganda requires that attendants undertake this role. Many patients in our sample accessed the hospital in the first instance through labour ward. This would then be followed by a short transfer along an external path connecting labour ward with gynaecology/post-natal ward along which large clusters of attendants sit, sleep and eat. More ‘high risk’ movements involve transfers of patients from critical care wards (when patients are admitted in emergency situations) and movements to and from operating theatres. Whilst emergency admissions were less common in our sample, the movements between post-natal ward and operating theatres was usual. To add further complexity to these movements it is usual for more than one attendant to be involved, usually accompanied by the attendants of other patients to help lift the patient onto and off a hospital trolley at either end of the journey:

[The attendant] went outside the ward to get the patient trolley. She then wheeled the patient to the main theatre. At 6pm, the daughter wheeled the patient with the help of 2 attendants of other patients back to the ward. She then took the trolley back to theatre [12]

In this case the primary attendant would have made six separate journeys between the ward and theatre, with one of these (return) journeys involving two attendants of other patients: a total of ten individual journeys. Attendants also accompany patients for routine tests including ultrasound scans. In the following case the
patient has three attendants; two accompany her for a scan whilst the grandmother who isn't feeling well sleeps on the patient’s bed:

_The grandmother returned to ward and slept on the patient’s bed as she was weak, and the niece went to the scan [department] to find the patient and her daughter [08]_

In one case a patient was required to move with her attendant to access a psychiatrist in the mental health ward which is some distance from post-natal ward and involves transiting through congested out-patient clinics. Another very common form of movement involves attendants travelling (without the patient) to and from hospital pharmacies to access medications. Reflecting the regular occurrence of stock-outs of drugs and consumables attendants make frequent journeys to the public and private pharmacies (located in the hospital’s private wing). Here they buy drugs and consumables including catheters, jik[8], nasal gastric tubes and urinary bags (see Case 14 below).

Attendants also access services, predominantly Outpatient Department (OPD) for their own healthcare needs. In one case an attendant went to the out-patient clinic to have a tooth removed [05]. In another, the patient’s attendant daughter was herself pregnant and visited the clinic for a scan before re-joining her mother and her niece [007]. Another case involved an unsuccessful trip to a very congested OPD:

_The attendant (mother) had to go to the outpatient department as she was not feeling well leaving the patient with the sister. After 30 minutes the mother came back without being treated because there were many patients there [06]._

**The ‘Two-body’ Problem: Caring for Newborn**

The sample for this study involved women in a post-natal ward. Inevitably this adds a major complexity, the presence of a second vulnerable patient. Attendants play a very major role in supporting newborn babies. In the first instance, a baby born in theatre is handed directly to the attendant present in the adjacent recovery room. Where necessary the attendant will also be charged with taking a baby directly from theatre to the neo natal intensive care unit (NICU). In 5 cases (14, 23, 28, 03, 08) the newborn baby’s condition meant that it had to be repeatedly moved between post-natal ward and the NICU. In such cases babies may be taken back to the mother for breastfeeding or the mother will be taken to the NICU to feed her baby. The NICU is based in the hospital’s private wing. The following case is cited in some detail as it illustrates the complexity of journeys with attendants exchanging roles to provide 24/7 care to both mother and baby.

**Case Study Illustrating Newborn Care**

_The theatre nurse came holding the baby and handed it over to the grandmother who was told to take him to NICU (neonatal ward) because of severe asphyxia. The aunt remained in the recovery room waiting for the patient. The aunt wheeled the patient to postnatal ward helped by the male attendant of another patient. The grandmother came back from NICU and the nurse gave her a file to go and pick drugs from the in-patient-pharmacy. The husband also came to the hospital to check on the patient with food from home. He came on the ward and sat at the end of the patient’s bed. The grandmother left at 9pm and went home. After the patient gained consciousness [the husband] went to NICU to check on the baby. He later emptied the urinary bag in the toilets. He went to the tank and got water for cleaning the patient and later served food to himself and tea to the patient. He later laid a mattress on the floor and rested. He woke up 3 times in the night going to NICU checking_
on the baby and the patient on ward. He went outside the ward to get water to wash the patient. In the morning he went to NICU to check on the baby and stayed outside because the ward was being cleaned. As he was still outside, the nurse from NICU came and told the husband to take the patient to breastfeed the baby. As the patient was in NICU breastfeeding, the husband went to the market to buy tea. He went back to NICU to bring the patient back to the ward where served tea. At 8am, the niece came with food from home and then left at 9am.

The husband escorted the patient again to breastfeed the baby in NICU then came back on the ward. The husband went to the washrooms, washed his hands and came back to serve food. [They] ate while sitting at the end of the bed. He went outside to wash utensils from the [water] tank near labour suit then went to wash clothes near paediatric ward.

The mother of the patient came [... she] sat on the bench with other attendants and started conversing with the patient and her husband. The husband went to the market and bought tea leaving the patient with the mother. The mother was told to go outside the ward with other attendants as the nurse was going to administer drugs. [The husband] then escorted the patient to NICU to breast feed the baby and went home leaving the patient with the mother. At 4pm, the mother was seen escorting the patient to NICU to breastfeed the baby then came back on ward. The mother went to wash the patient's clothes near paediatric ward. After washing clothes, she served food and tea to the patient and herself and then washed the utensils from the tank near labour suit. The mother woke up at 7pm, went to the market bought tea and yellow banana and came back on ward. At 10pm, the husband laid a mattress on the floor under the patient's bed and slept. As the nurse was going to administer drugs, the mother went outside the ward then came back laid a cloth on the floor and also slept [14].

This case has been presented at length to illustrate the complexity of social movements involved and the critical roles that attendants are involved in. It also demonstrates the intense engagement of men even in societies where most care is performed by women. The volume of journeys, numbers of people involved and the tasks they are required to undertake will come as a shock to those not familiar with public hospitals in LMICs.

Attendants also play an important role taking babies to the Out-Patient Clinic for immunisation before they go home. The examples given above involved access to health services within the hospital. Many more journeys are made across hospital grounds to support the wider well-being of patients and co-resident attendants. These activities can be grouped into 3 broad areas: supporting ambulation, nutrition and hygiene.

Encouraging patients to ambulate post-c-section is essential to their recovery and ability to care for their baby and return home. This task was explicitly evidenced in 7 cases most of which involved helping patients to move around the hospital grounds:

The husband called the nurse on duty to disconnect the drip as the patient wanted to ambulate. The patient went outside to ambulate with her daughter [05]

The overwhelming majority of attendant movements are undertaken in order to ensure patients (and the attendants themselves) are able to access drinking water and food. The literature does draw attention to the importance of hospital visitors in supporting nutrition and occasionally, hydration. Unfortunately, few papers give any detail on how this process takes place and what kinds of movement and social contact are involved. Montesante et al, for example, talk of family caregivers providing essential 'nutritional support' (2023: 5) but it is unclear if this means encouraging patients to eat hospital-provided meals or providing occasional fruit and
snacks. Hung et al (2020) similarly refer to the role of companions in ‘the daily living and care, including cleaning, diet, rehabilitation, handling in and out of the hospital (2020:1112) but once again we don’t know what kinds of activities, movements and social contacts this involves. Whilst Sultana et al (2008) mention the role of attendants in ‘feeding’ and Zulfiqar et al (2013) refer to the ‘easy availability of food from charity organisations’ on the hospital site, no detail is provided to indicate the actual activities involved. We are left to assume this involves encouraging patients to eat meals provided by the hospital and delivered directly to the bedside. It was interesting (but perhaps not surprising) to see one study reporting poor adherence to medication and nutritional guidance when family carers were more present (Zulfiqar, 2013). More commonly papers reported negative impacts on nutrition with Hindmarch et al suggesting that visitor restrictions in long term residential care resulted in some patients losing weight and stopping eating. Here the authors concluded that family caregivers in Canada are giving ‘life and death’ care (2021: 197). This is undoubtedly the case in our Ugandan context where this may not be so much about encouraging patients to drink and eat but rather them taking full responsibility for providing clean drinking water and preparing tea and food.

It is rare in public facilities in Uganda for patients to have access on the wards to free, safe, drinking water despite its importance to recovery. Neither food nor clean drinking water are provided routinely by public hospitals in Uganda. It is unsafe to drink tap water in Uganda without first boiling it. Few patients can afford to buy bottled drinking water. Attendants play a critical role then in sourcing water for hydration and washing patients. Repeated journeys are made for this purpose including trips to town, trips to the hospital kitchen (to boil water and cook) or outside taps near the TB ward and labour ward:

**The sister went to the hospital kitchen to prepare tea. [18]**

In one case the patient was advised to drink water prior to an ultrasound scan and this had to be bought by her attendant from the staff canteen:

*The scan lady told the neighbour to buy water for drinking so as to have a full bladder which she bought from the hospital canteen. [22]*

In other examples, attendants bought water from vendors who physically came on the wards:

*The mother woke up at 5am by the hawkers who were selling hot water on the ward. [She] bought 2 cups for cleaning the patient and the baby. [13]*

*[She] bought hot water within the ward for cleaning the patient. [Later] the daughter went outside hospital to the market and bought hot water for cleaning the patient. [12]*

Journeys to buy water are often combined with purchasing or preparing food and typically take place several times a day and involve different locations and individuals. It is rare in Uganda for people to consume cold or packaged food in part due to the lack of refrigeration. In practice this means that attendants are constantly busy either buying food from local markets, bringing it from home or buying produce and preparing food in the designated hospital kitchen (a large, covered space where attendants cook on their own charcoal fires). The following case is illustrative and involved several attendants:

*The sister and mother went to the kitchen that is near surgical ward to prepare breakfast [10]*
There is a small shop at the hospital canteen which some attendants use to buy basic supplies:

[She] was told by the nurse to go and buy jik, washing powder and bought them from the shop within the hospital [14]

In addition to hydration and nutrition, attendants play an essential role in washing cooking utensils and plates etc. and washing patients’ (and their own) bed linen and clothes. Laundry is performed (manually) near the paediatric ward where washing lines are available:

The sister went to wash the patient’s clothes near the paediatric ward and hanged them on the wireline near labour suit [10]

As noted above, it is not only people who move around. Attendants carry huge volumes of luggage including clothes, bedding, cooking equipment and washing bowls. These items are in constant motion as attendants move on and off the ward and into and out of the hospital. Movements between labour ward, post-natal ward and theatre were typical:

[The attendant helped] shift the patient’s luggage from labour suit to postnatal ward [09]

The time of the day has an important impact on these activities as many attendants bring all their mattresses, buckets, bowls, cooking utensils etc. onto the ward to sleep on the floor at night. They are also required to leave the ward with these items during ward rounds and cleaning:

They were woken at 5am by the cleaner and night nurses who were going to do their duties, so they sat outside on the floor. During the ward round the husband sat outside the ward on bench [05]

Uganda has two ‘rainy’ seasons. When it rains attendants staying outside will come onto the wards as there is no covered area for them to wait.

Community Mobilities

Human movements connecting domestic and community settings with public health facilities are a primary cause for concern when it comes to infection transmission. This is perhaps most evident during a pandemic, but applies equally to more mundane nosocomial infection transmission, and in the Ugandan context, Ebola. It is important to remember that this is a bilateral process facilitating not just the transmission of infection from communities into health facilities but also from those health facilities into communities. Accompanying this is the transfer of genetic traits leading to an increased risk for the development of antimicrobial resistance in both community and hospital settings.

Whilst these movements may pose a lesser threat to short-term direct patient outcomes, they create a longer-term risk to health workers and vulnerable people in the home/community setting (including children, elderly people and people with comorbidities). Whilst various innovations were seen in high income settings during COVID-19 to reduce hospital stays, including the use of telemedicine and self-management, in low resource settings a physical journey is usually required involving both patients and family members. Dysfunctional referral systems also mean that patients commonly ‘choose’ to access referral hospitals directly rather than through community health facilities contributing to severe congestion.
Transporting Patients and Attendants to Hospital

Fort Portal Regional Referral Hospital supports a wide catchment area. Many patients will make long and complex journeys. Figure 3 identifies the home locations of all 30 patients in the sample.

The mode of transport included private vehicles either owned by the family or borrowed from friends or neighbours; vehicles owned by organisations (such as health facilities and including private ambulances) and public means (boda-bodas and matatus). Boda bodas are motorcycle taxis often carrying 2–4 passengers. From a Road Traffic Accident (RTA) perspective bodas are the least safe mode of transport (Nantulya and Reich, 2002) but they may carry a lower risk of infection spread. Matatus, on the other hand, are vans carrying 15–20 passengers in very congested proximity. The most common (and cheapest) mode of transport involved the use of boda bodas. Eighteen cases cited the use of bodas followed by matatus (7 cases).

Complex Journeys through Referral Facilities

Adding further complexity to the community-healthcare acquired infection distinction, it is very common for patients and attendants to pass through several health facilities on their way to hospital.

In theory most maternity cases should be dealt with in lower-level community-based health facilities, including Health Centre IV facilities with operating theatres. They should only be referred to hospital if there is a complication or emergency. Respondents described more complex routes transiting through one or more public or private health facilities along the way adding to the potential for infection transmission between multiple settings:

*The patient called a female neighbour who took her to Yelya hospital in Kibiito where they spent one night. The doctor found the patient was very anaemic due to severe bleeding and referred them to Kibiito Health Centre 1V for a blood transfusion. The doctor in Kibiito then referred them to the regional referral hospital because they had no blood. For this final journey the patient and her neighbour used a motorcycle then boarded public means of transport (matatu) with other passengers up to Fort Portal then boarded another motorcycle from town to the hospital [22].*

This patient travelled through three health facilities. The final journey involved a woman in a critical condition and her neighbour boarding a congested matatu and two boda bodas.

Other Home-Hospital Journeys

Whilst patient and attendant travel to seek care is unavoidable, there are multiple cases of repeated journeys made by attendants during the patient’s hospital stay. Attendants spoke often of returning ‘home’ to fetch food, clothes, mattresses, washing utensils and for personal bathing. In other cases, the attendants may have to return home to undertake other work or caring-related responsibilities. In such cases attendant duties are shared with other family members or friends:

*After eating, the village friend decided to take the dirty utensils home to be washed from there as they were many (for breakfast and lunch). He was escorted by an aunt to the main gate. [Later] the niece went home to bathe as it was near the hospital. She bypassed the market, bought milk which she went home to prepare (boil) and returned to the hospital [29]*
Such cases really challenge any attempts to distinguish nosocomial from community-based transmission. In the following example, the patient’s mother went home to wash as she felt the patients’ washrooms at the hospital were unclean (a common observation). She also used this opportunity to bring hot water into the hospital to wash the patient and baby:

*The mother went back home to bathe fearing to get infections from the hospital washrooms. She came back on ward with hot water from home for cleaning the baby and the patient* [30]

Zulfiqar’s respondents made a similar observation in Pakistan in this case noting the lack of public toilets in the hospitals which required attendants to use toilets outside the hospital adding to infection risks and movements (2013:146). Whilst there were some toilets for attendants at the far side of the hospital during the study period, recent changes have seen the introduction of charges to attendants using even these toilets.

Other common reasons given for repeat journeys home included collecting a mattress to sleep on [08] and charging mobile phones [30]. In the next case 2 different family members returned to separate homes each bringing different items for the patient:

*The sister-in-law came from home with the basin, plates and cups to use in the hospital ……The husband came to the hospital from home with bedsheets* [10]

Attendants play an essential role in supporting patients in hospital. This includes the provision of food and water. In all 30 cases various movements were observed fulfilling this function. The food is either brought from the local market or from home. It was very common for attendants to travel home, or for other attendants from home to join the family, for the purposes of bringing food into the hospital. Eating together as a family, often sat on the floor next to the bed also played an important social role:

*She came with food from home, served them and herself. They sat on the floor to eat then after also fed the patient* [05]

In the following case the patient had travelled from her workplace rather than her home adding a new dimension to community spread:

*She came from her workplace and passed by the hospital to check on the patient. She had come with food* [09]

The next case illustrates some of the dynamics of dual caring roles which, in this case, meant that one of the attendant’s young children was brought to the hospital at night by another family member to be breast fed:

*The attendant’s niece brought the attendant’s baby from home. Asked why her baby comes and goes, the attendant said she breastfeeds her baby at night as she can eat and drink during day* [29]

Bringing children into the hospital to join patients and attendants was quite accepted behaviour, even during COVID-19:

*The aunt had gone home and returned with her children (including one aged 7 months)* [03]

In many other cases attendants made repeated journeys from the hospital to the local town to buy food, water or commodities:
The daughter and her friend went to the market to buy food. The daughter later went to the market to buy tea for the patient. The following morning the daughter went to the market to buy breakfast - she went back to the market again to buy more breakfast because the one bought was not enough for all of them [07]

The sister went outside the hospital gate to buy hot water for bathing and to buy tea [10]

It is also common for attendants to go to town to purchase medical supplies not available on site:

The patient's sister went to buy a [nasogastric] NG tube from a pharmacy in town as it was not available in the hospital's private pharmacy [03]

Discussion

The data presented in this paper casts a unique lens on the activities that constitute informal caregiving in a Ugandan public hospital, during the COVID-19 pandemic. It is the only international study that we are aware of that provides a granular insight into attendant behaviours and associated risks. The data challenges the fundamental tenets of the ‘compassion versus infection control’ dichotomy that has shaped policy. This binary is unhelpful for a range of reasons. In the first instance, research concurs on the lack of any real evidence on the contribution that hospital visiting plays in the transmission of infection (Forsberg et al 2023). Maurand et al speculate on the contribution that visitors may play as ‘virus reservoirs’ and ‘asymptomatic shedders’ but conclude that additional studies are needed (2023:12). Wee et al (2021) responded to a call for further evidence of the contribution that hospital visiting makes to health care-associated transmission of respiratory viral infections. Their study in Singapore included hospital visiting restrictions as part of a wider ‘bundle’ of IPC measures. In the first instance the results suggested reductions in visiting contributed to a successful reduction in healthcare worker transmission. However, subsequent relaxation of visiting restrictions did not trigger an increase in transmission. Muniraman et al (2020), Wendlandt et al (2022) and Stemler et al (2022) go further arguing that multiple studies have shown that hospital visiting is not a major source of infection transmission. All the papers discussed above are drawn from research in high income settings. As such they fail to capture the granular quality of hands-on care in low resource settings. The findings presented in this study raise serious concerns about the role of attendants as bilateral vectors of infection. It would be foolhardy to suggest otherwise particularly as attendants undertake activities without access to or compliance with basic resources (clean water and washing/toilet facilities) or IPC protection.

Secondly, the dichotomy compounds a generic characterisation of informal caregiving as ‘compassion’. Definitions of compassion, in well-resourced settings, at least, tend to equate it with feelings of pity or sorrow for others – of emotional connections and psychological well-being. They remind us of the distinction Finch and Groves (1983) made between ‘Caring-About’ (considering a person's well-being and happiness and perhaps organising the activities associated with that) as opposed to ‘Caring-For’ – the more gendered process of actually doing for a person what they cannot do for themselves. Attendants in the Ugandan public setting care for patients in an immediate hands-on fashion undertaking tasks that in most high-income settings fall firmly within the responsibilities of the health system and are risk-mitigated through IPC measures. This includes basic nursing care with an emphasis on patient safety, personal hygiene and nutrition.

What is absolutely clear from this study is that attendants provide life-and-death care augmenting and supporting health workers. The question remains: how can we best design interventions that mitigate risks (to all
concerned) whilst enabling and actively supporting informal caregivers in public facilities in low resource settings?

The volume of patients accessing Referral Hospitals in Uganda reflects the inadequacy of existing referral systems with many patients voting with their feet and self-referring direct to the hospital. This is a complex systemic problem, particularly in maternity services where a combination of poor quality and mistrusted primary care services combined with endemic delays serve to congest hospitals (Ackers and Ackers-Johnson, 2017). Ultimately decongestion through investment in lower-level facilities, closer to patients’ homes, would have a dramatic effect.

The lack of a formal policy on hospital visiting in Uganda provides an opportunity. Certainly, a significant proportion of attendant movements could be reduced through measures to provide proximate access to water, food, shelter and medicines. Enforced policies on attendant numbers and the presence of children are urgently required. Hung et al talk of the need to generate an evidence-base to challenge the ‘companions’ culture’ in Taiwan so that families understand that ‘avoiding unnecessary visits in hospitals are true displays of medical courtesy’ (2020:1115). Ultimately, recognition that attendants play a critical role in supporting health workers and patients needs to be reflected in actioning their right to publicly funded IPC enablers.

Declarations

Author Contribution

LA managed the project and lead data analysis and writing. RN collected the data and supported data analysis. GA advised on the microbiology aspects of the data analysis and antimicrobial resistance literature and writing. RH was a key stakeholder, reviewed the text, advised on the policy context and reviewed the text.

Data Availability Note

As the data is qualitative, sensitive and very difficult to anonymise we will not be making it available for public use.

Authors Contributions

Professor Ackers conceptualised the study and co-designed the methods with Ackers-Johnson and Namiiro. Namiiro collected the data under Ackers’ supervision. Ackers and Namiiro analysed the qualitative data. Ackers-Johnson assisted with research review and writing. Mugahi contributed policy context and read and reviewed the paper.

References

1. Ackers-Johnson, G. (2020). Comparing the antimicrobial diversity of Staphylococcus aureus strains isolated from clinical cases of infection and those found as a commensal organism in Fort Portal, Uganda (PhD research).


**Footnotes**

5. HSR1920-109

6. A type of bleach used in all forms of cleaning.

7. Women with septic wounds are moved to the gynaecology wide of the ward.

8. Patients are often required to provide jic in the hospital.

**Figures**

![Figure 1](image-url)
Figure 2

A Floor Plan of the Hospital Complex showing Key Locations Accessed by Attendants
Figure 3

Home Locations of the Patient Sample