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Indispensable yet invisible: A qualitative study of carer roles in infection prevention in a South Indian hospital

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Contributorship Statement

Surya Surendran contributed to data collection, analysis, original draft, subsequent editing and final draft.
Enrique Castro-Sánchez contributed to data analysis, original draft, subsequent editing and final draft.
Vrinda Nampoothiri contributed to data collection, analysis, and editing drafts of the manuscript.
Shiny Joseph is a patient representative from India site, contributed to access to teams, patients and carers, revision of drafts.
Sanjeev Singh is country level principal investigator and contributed to study inception and access to sites, teams and data, data gathering, interpretation, and revision of drafts.
Carolyn Tarrant contributed to study design, data analysis and contribution to drafts of the manuscript.
Alison Holmes is study principal investigator, contributed to study inception, design, and editing of drafts.
Esmita Charani contributed to study inception, design, data collection, original draft, subsequent editing and final draft.

Competing Interests

Enrique Castro-Sánchez is a WHO consultant in antimicrobial resistance implementation. Sanjeev Singh and Shiny Joseph are employed at the study site beyond the study's capacity. Other authors have no conflicts to declare

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Highlights

- This work sheds a light on the lack of acknowledgement of the role of carers in infection prevention and control (IPC) practices by the international, national, and institutional guidelines and by healthcare systems.
- Carers have critical roles to play in: 1) the physical environment of the patient, often engaging in activities not only limited to direct personal care (i.e. bathing patients) but also clinical tasks (i.e. wound care) which would bring them in contact with the patient; 2) contributing to clinical decision making through the knowledge they have in relation to patient medical history and condition.
- Carers do not receive standard, or formalised education or training to support these roles.
- The IPC policies and practices need to take into consideration different cultural contexts including those in which families are responsible for indispensable inpatient care.

Abstract

Objectives We investigated the roles of patient carers in infection-related care on surgical wards in a South Indian hospital, from the perspective of healthcare workers (HCW), patients, and their carers.

Methods Ethnographic study including ward-round observations (138 hours) and face-to-face interviews (44 HCW, 6 patients/carers). Data (field notes, interview transcripts) were coded in NVivo 12 and thematically analysed. Data collection and analysis were iterative, recursive and continued until thematic saturation.

Results Carers have important, unrecognised roles. In the study site, institutional expectations are formalised in policies demanding a carer to always accompany inpatients. Such intense presence embeds families in the patient care environment, as demonstrated by their high engagement in direct personal (bathing patients) and clinical care (wound care). Carers actively participate in discussions on patient progress with HCWs, including therapeutic options. There is a misalignment between how carers are positioned by the organisation (through policy mandates, institutional practices, and HCWs expectations), and the role that they play in practice, resulting in their role, though indispensable, remaining unrecognised.

Conclusion Current models of patient and carer involvement in infection prevention and control (IPC) are poorly aligned with socio-cultural and contextual aspects of care. Culture-sensitive IPC policies which embrace the roles that carers play are urgently needed.

Keywords: Patient and carer role, Family-centred care, family involvement, Infection Prevention and Control practices, low- and middle-income country

INTRODUCTION

Healthcare systems worldwide have increasingly embraced patient-centeredness, encouraging the involvement of patients in decisions about their care(1–5). Capturing and amplifying the patient experience in healthcare settings, however, remains understudied. Despite much progress, vast disparities remain between the ability of health systems to provide patient-centred care(6). Reviewing the existing evidence, the majority of the limited infection related patient involvement initiatives in inpatient care originate from high income settings(7). This gap in evidence limits the generalisability of findings, as the healthcare worker and patient relationship, and citizens' access to and perception of healthcare vary across cultures and countries, shaped by socioeconomic and cultural determinants(8,9).

In addition to these sociocultural influences, the balance between medical paternalism and patient autonomy is constantly being tested and challenged by multiple factors, including the availability of information and access to therapies on the internet or social media(10). The role of family members adds further complexity, as their roles as carers and co-dependents are often overlooked(9). This oversight may be particularly significant where societal structures and cultural traditions attribute greater importance to patient's social networks(11). For example, in many low- and middle-income countries (LMICs), people live amongst extended family members which may include several generations in the same household, sharing not only a physical space but also economic resources, and mutually benefitting from social and cultural activities and assets(12). From a sociological lens, when a person is ill, they experience not only a biological process but may also need to adjust their behaviors and often withdraw from routine social roles(13). This can impact the lives of their family members who may be required to assume the role of carers(14). Furthermore, during the patient's admission to hospital, family members and carers provide not only psychological and emotional support to the patient, but also often act as custodians of vital clinical information, and more importantly continuing patient support through recovery and convalescence(15).

The involvement of family members in the inpatient journey can shape clinical activities, including infection prevention and control (IPC) practices(14). Evidence highlights the vital role played by carers in enhancing the wellbeing of patients, improving clinical outcomes, such as surgical wound healing(16). Whilst the need to recognise the influence of carers and their role in IPC has been mentioned in WHO guidelines, which advocate for partnerships between the patients, their family and the healthcare providers to improve practices such as hand hygiene in healthcare(17), much progress remains to be made in integrating this approach in national and local policy and guidelines(14).

The effect of carers' roles and activities on the risk of spread of healthcare-associated infections is not well understood. This may be partly due to the ambiguity and informal approach to the role of carers and indeed patients whilst they are hospitalised. Where research exists, it highlights the lack of clarity about roles, and insufficient information provided to them about expected IPC practices(14,16).

As part of a larger international study(18,19) investigating and optimising infection-related care in surgical pathways, we sought to explore the extent and nature of the involvement of carers in the experience of patients undergoing surgical procedures. We included the perspective of a wide range of stakeholders including healthcare workers (HCW), patients, and their carers. In our study we defined 'carers' as family members, friends, or any other person associated with the patient who provided care for them either when hospitalised or at home, without expecting any financial return.

METHODS

Setting

The research was conducted in a 1350-bed, not-for-profit, tertiary hospital in south India. This hospital represents an atypical setting in the Indian context as state-of-the-art clinical management and a well-established IPC team were available. Two surgical departments, gastrointestinal surgery and cardiovascular surgery, were included in the study. These departments were selected as they represent specialties with high rate of operations requiring post-operative care and recovery.

Population

Using purposive sampling, HCW in the selected teams and patients who underwent surgery, and their carers were eligible to be included in the study (Supplemental file 1, participant demographics).

Data collection methods

Data were gathered by researchers between June 2018 and October 2019. The ethnographic study included non-participant observations, semi-structured face-to-face interviews with patients, carers and HCW, and documentary analysis.

Observations were conducted using an observation guide developed by the researchers and implemented in different healthcare settings(18,20). Data collection took place during routine surgical ward rounds and outpatient clinics. Researchers observed HCW conducting routine clinical services in relation to the patients under their care, including any communication or interactions that occurred with patients and their carers. Specifically, data were gathered from any practices that included interacting with the patient or patient bedside surfaces and would be classified as infection related care including wound care, hand washing, checking lines or catheters, administering medicines to the patient. HCW involved in ward rounds were invited to participate in interviews. Patients who developed infections after surgery were also invited to participate in interviews, along with their carers. A semi-structured interview guide was used to investigate the perspectives of participants on their roles and responsibilities in relation to

antibiotic use and IPC care. The interview guides were tailored to HCW and patients/carers (observation and interview guides in supplementary file 2). In addition to the interview guide, questions that arose during the observations and interviews were also explored. HCW interviews took place away from clinical duties at a mutually agreed to location and time. Patient and carer interviews took place at the bedside, or a vacant room when the patients were not receiving any medical intervention.

The interviews were conducted in a language comfortable for the participants, either English or Malayalam, the local language. All interviews in Malayalam were conducted by S Surendran and VN. Interviews were audio recorded and transcribed verbatim to English. The English translation was cross-checked for accuracy to the original transcriptions in Malayalam by S Surendran and VN.

Data relevant to infection related care that considered the role of patient and/or carers were retrieved from the existing international, national and hospital guidelines to provide contextual information. Relevant hospital-wide policy and guidelines were retrieved from the IPC leads in the hospital. National and international guidelines were retrieved from the official websites of WHO, Indian Council of Medical Research, India National Centre for Disease Control, and India National Accreditation Board for Hospitals and Healthcare Providers.

Data analysis

Field notes and transcripts were coded line by line using NVivo 12 software and analysed thematically using a constant comparative approach(21). A coding framework was developed based on emerging themes. This framework was further discussed and finalised among the researchers after an initial set of coding. The agreed framework was then used to code the remaining data and any emerging codes were discussed in further meetings. Data collection and analysis were iterative, recursive and continued until thematic saturation was achieved, that is, when no new themes were revealed(22).

The categories and relationships within the themes were explored to develop the theoretical statements. The policy and guidelines were reviewed for any references to patient and carer roles in IPC practices. Additionally, the clinical records of the patients who were included in the study were reviewed by the researchers to provide contextual information and to help the researchers compare the responses of the patients the documented account of their care whilst in hospital. Methodological and analytic triangulation was achieved through using data from interviews, observations, and documentary analysis. The findings were discussed iteratively with co-authors as part of identifying and developing themes. These findings were further fed back to the surgical teams participating in the study in a meeting.

Ethical Approval and participant consent

Ethical approval was granted by the Institutional Ethics Committee at Amrita Institute of Medical Sciences (IEC-AIMS-2018-INF.CONT-005A). The study was advertised to patients, carers and HCWs in the hospital via posters on the premises of ICU, wards, and the outpatient clinic. The researchers held an introductory meeting with the healthcare team and gained their written consent for ethnographic observations before data collection had commenced. In addition, the researchers introduced themselves to new healthcare teams, patients, and carers prior to or during the observation. Before the interview, participants were provided with the study information leaflet and they were verbally informed that their participation was voluntary, that data would be kept confidential, and what they said would have no impact on the care they were receiving at the hospital.

RESULTS

Data were collected from over 138 hours of observations, 44 interviews with HCW and 6 with patients and carers (one interview was conducted with only the patient). We observed over 800 episodes of HCW and patient and carer discourse during the ward rounds. This gave us

insight into the carers' roles and responsibilities in the patient pathway. The following table (Table 1) summarises the data gathered.

Table 1: Data collected through the different methods used

Three themes emerged: policy mandates and expectations on carer involvement, the indispensable yet invisible role of carers, and inconsistent carer education.

Policy mandates, institutional practices, and HCWs expectations about carers involvement

International and national IPC guidelines articulate a procedural involvement of carers, centered on how to perform tasks such as hand hygiene or donning of personal protective equipment (PPE). Carers are not seen as an asset but as individuals whose presence and behavior potentially presents an infection risk to patients. For example, special precautions for isolated patients, include restrictions for visitors together with education of carers about hand hygiene and PPE is largely identified by all major guidelines.

"Tailored IPC education for patients or family members should be considered to minimise the potential for healthcare associated infections." Improving infection prevention and control at the health facility(23)

"Whenever family members assume care activities, they should receive tailored IPC training in order to protect themselves and their loved ones and thus minimise any possibility of cross transmission." WHO minimum requirements for Infection Prevention and Control programmes(24)

The National Accreditation Board for Hospitals & Healthcare Providers (NABH) and recent National Centre for Disease Control (NCDC) guidelines recognise the need for effective PPE for family members as standard IPC precautions. The institutional guidelines in the study site,

only referenced patient education on signs of surgical site infections and wound care, with no reference to the role of carers.

The study hospital, however, mandates that a carer be always present with the patient, to the extreme that a patient would not be accepted for hospital admission without a carer.

"One attendant should be allowed to stay in the ward with the patient who should be taught to practice hand hygiene before and after touching the patient." NCDC National Guideline for IPC in Healthcare facilities(25)

The hospital justifies this approach through recognising that a person is needed to run errands (for example, buy medications or pay bills) for which there is no designated staff members and patients cannot go themselves. The hospital environment is also adapted to enable and facilitate the carers' activities. For example, by providing beds for carers next to the patient on the wards. In the intensive care unit (ICU), carers are only allowed during visiting hours.

This relative invisibility of patients and carers in guidelines and policies was corroborated in the views expressed by HCWs, who consider the patients and carers roles in IPC to be restricted to hand hygiene practices (Table 2, section T1 a). Despite this HCWs still expect the carers to perform IPC related activities whilst in hospital or at home (Table 2, section T1 b). They also recognise that the mere presence of carers in the hospital for prolonged periods can pose potential risk for spread of infection. This role is exacerbated in ICU, compared with general care wards, due to structural deficiencies mitigated by the presence of the carers (Table 2, section T1 c). For example, though all care is provided by HCWs in ICU, on the wards carers support the patient and are expected to be involved in their care. They perform a range of personal care tasks such as bathing, acquiring medicines for them and feeding them, etc. (Table 2, section T1 d).

Carers have indispensable presence at patient bed space yet are invisible

The common term used in the Indian context to describe family members or friends who accompany patients to the hospital is ‘bystander’. This word was referred to in the local policy and was used in general conversation. From this point forward we use the term carer for consistency, except when referencing data where the term bystander is used, instead. Carers are a constant presence in the physical environment of the patient, often engaging in activities which would bring them in contact with the patient (Table 2, section T2 a and b). They are involved in supporting the patients for their regular day-to-day activities, both during the hospital stay (Table 2, section T2 b) and during convalescence at home. Sometimes, family members take turns and stay with the patients (Table 2, section T2 c).

Carers are approached by HCWs for a range of activities, from fairly mundane such as obtaining details regarding the patients, to crucial decisions that need to be made about clinical care (Table 2, section T2 d). It was common for HCWs to directly educate carers about patient care. This was observed during ward rounds, where whilst the patients were asked about how they were doing by the HCWs, the clinical decisions to be made were discussed with the carer. There were also instances when HCWs withheld all or some of the clinical information from the patient, at the request of the carers, leaving them responsible for decisions (Table 2, section T2 e and f). Since communication happened mostly between the HCWs and carers, decisions regarding patient care were sometimes negotiated exclusively by the carers. In turn, patients often reported in the interviews that they had no idea about what was happening in their care (Table 2, section T2 f). Often, when a patient was interviewed in the presence of a carer, the carer contributed more information regarding the patient health progress than the patient themselves (Table 2, section T2 g).

Post discharge, family members become the primary caretakers responsible for patient health, hygiene and medications. This includes dressing wounds regularly and monitoring for signs or symptoms of infection in the surgical site (Table 2, section T2 h). There is a belief that

infections are ‘brought in’ by other visitors (Table 2, section T2 i), resulting in recently discharged patients being kept at home (Table 2, section T2 j), where the environment could be controlled and visitors restricted (Table 2, section T2 k). The patient and carers also assume roles that traditionally would be the remit of the HCWs such as chasing culture results and querying infection management (Table 2, section T2 l).

Carer support and education is inconsistent

The complex role played by carers is unrecognised and unsupported. Carers do not receive any standard, or formalised training to prepare them for their role, nor indeed do the patients. Post discharge tasks carried out by carers become even more clinical. For example, whilst nurses arrange wound care during the hospital admission carers will pick up responsibilities for such care and dressing techniques by observing HCWs and learning on the go (Table 2, section T3 a). Before patients are discharged, carers receive instruction from HCWs during ward rounds (Table 2, section T3 b), and may receive information leaflets on infection prevention. Such training and information provision for carers however is not routinely provided, risking wound contamination and infection (Table 2, section T3 c).

Table 2. Key emerging themes from data collected through observations and interview

DISCUSSION

This study has identified that the paradoxical position of carers in the Indian healthcare context. They are indispensable yet invisible to HCWs, and often overlooked in institutional policies, including IPC protocols as described in this study. The carers are considered by HCWs and administrators as being too peripheral to patient care roles to feature in IPC policy or guidelines. Despite this, in this study they were often very involved in patient care, making critical decisions for patients. Carers do not receive any training or support to perform this role and are reliant on learning from observing HCWs carry out specific tasks during the patient's stay. This potentially risks misunderstandings of practices or indeed adopting wrong practices, which could harm the patient. Carers bring their own expertise and knowledge of the individual patients' illness that should be acknowledged in efforts to include them as part of the care team. Whilst not observed in this study, we cannot rule out that carer practices may also be determined by their own beliefs and knowledge shaped through sense-making(26). Therefore, we should not only consider the knowledge the patient brings to their care, but also the knowledge the carers may bring to patient care(27). Effective engagement with carers will benefit from the recognition of the 'non-technical' or experiential domains of caring, and the integration of 'different meanings of expertise'(27). Key recommendations have emerged from this work which we have summarized in Box 1, and discus them in more detail on the following sections.

Policies tend to focus on reducing the infection risks posed by carers' presence and behaviour or identifying a role for them in encouraging health professionals to perform IPC practices, for example, challenging health professionals to wash their hands. Instead, we need to recognise them as a critical resource who, if supported and educated adequately, could contribute to the care of patients in the hospital and on discharge in the community. In settings where families remain at the patient bedside to assist health professionals, care roles have been largely

overlooked. This has meant carers are unprepared and unsupported in these roles, receiving little training or guidance. Studies reporting on education of family members have detailed benefits on IPC outcomes. For example, a study aiming to reduce ventilator-associated pneumonia among ICU patients using multimodal interventions including posters and 'scripts' prepared for the ICU team to educate family members of critically ill patients obtained significant reduction in ventilator associated pneumonia rates, enabling carers to participate in patient care(28).

A study investigating the inclusion of patients and their family members in IPC policies and guidelines across Bangladesh, Indonesia, and South Korea identified that many key activities were carried out by carers, and that the degree of dependence on family members as caregivers was similar to those provided by HCW in the global north(14). Therefore, facilitating HCW interactions with the carers and recognizing their roles as legitimate members of the patients care team, has the potential to lead to optimised patient outcomes. This will enable carers to have a better understanding of patients' IPC needs, to supplement the important contextual information they already have with regards to patient care. Furthermore, engaging with carers in optimal practices around infection-related care in hospital and at home may reduce the transmission of infection.

Our review of global IPC policies identified the gap in inclusion of carers in existing infection related recommendations in secondary care settings. This gap may be due to several factors. Firstly, different cultural and societal norms will dictate the roles that the social network of patient plays in their healthcare, as evidenced by our findings and reported in other studies (14). Secondly, the different models of healthcare and the economic investment of governments in their healthcare infrastructure(29) play critical roles in the need for pro bono effort from those socially connected to the patient. Thirdly, advocating for holistic carer involvement presents dilemmas about 'semi-professionalising' carers, blurring the line between supporting a relative and expecting them to assume responsibilities that should

belong to HCW. Equally, it presents the risk of marginalising those patients who do not have a social network of family members or carers willing or able to assume these responsibilities. There may also be reluctance from HCW to embrace such assets as it may disrupt the patient care pathway by introducing unqualified people that they will be required to co-operate with. Furthermore, carers may be left overwhelmed as they will be required to work not only with hospital doctors and nurses, but also community HCW.

In addition to this transactional perspective, where carers' skills should be enhanced due to the potential benefits to clinical practice and patient outcomes, patients and their carers have the right to understand the changing circumstances of their treatment. Being outsiders to the clinical setting, patients and carers often do not know about infections and the reason for their occurrence. If due attention is paid towards improving their knowledge, this could help in prevention and early identification of infections thereby decreasing the additional burden of care.

Patient involvement is increasingly seen as imperative for good and effective care, as part of a drive towards patient-centeredness – an emerging concept(30). We advocate for 'family-centred care', and support for carer involvement, as aspirations to effective infection-related care. This would involve formally acknowledging the role carers play, as well as shaping policies including those on IPC to support, promote and strengthen carer involvement. Whilst international guidelines on patient care propose that national strategies tailor patient and carer education to the local context, such tailoring may require that family-centeredness is adopted and promoted to fit to the cultural norms and traditions.

Limitation of study

This study has several limitations. The transferability of the results to other contexts and settings may be limited and would require contextual consideration. The study was conducted in a hospital at the forefront of implementing interventions and policies with respect to IPC and

AMS practices and sensitized to patient safety and patient experience. These characteristics may be atypical in the local or national context and may also be uncommon in other international settings(7). Furthermore, the study was carried out in a state in India with high levels of literacy and a healthcare system featuring a comprehensive public health system with active patient and public engagement initiatives(31), which may influence the roles held and expected by carers, as well as their interest and ability to participate in care decisions, and the comfort of healthcare workers towards such shared decision-making.

The research team included local and international researchers. To balance the experiences, assumptions, and beliefs the team may have had about the emergent results, open discussions were regularly held among the team members to ensure that the interpretation of the findings recognized their positioning. Co-authors SS, S Surendran and VN represented both insider and outsider perspectives in their roles. Further, senior author EC had spent a significant time in the hospital site over several years, including during her PhD studies, investigating culture and context and its influence on IPC and antibiotic prescribing behaviours(31,32). Though contingent steps were taken to check the accuracy of the English translation of the interviews conducted originally in Malayalam – including the same local researchers conducting the interviews and cross-checking the translation – it is possible that the translation may have influenced the interpretation of the findings.

As the objective of the larger study was the optimisation of antibiotic use and IPC practices along the surgical pathway, only six patients/carers were interviewed versus 44 healthcare professionals. However, we drew from observations (including over 800 episodes of carer/patient and HCW discourse) to develop a deeper understanding of carer roles.

CONCLUSION

In the Indian context patient carers remain an indispensable yet invisible resources for infection related care. Current IPC guidelines and principles may overlook the wider socio-cultural contexts, particularly in LMICs, and the constellation of persons who play a role in care and by extension decisions about IPC practices. Culture-sensitive IPC policies which embrace the roles that carers play are urgently needed. Furthermore, there needs to be a better understanding of the knowledge that patients and their carers bring to the infection related care and practices which may influence health outcomes.

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Table 1.

Methods used		Quantity	Target population	Relevance of the data gathered to the study
Non-participant observations	Broad scope observation	138 hours of observation, including patient/carer and HCW discourse	All stakeholders, including carers and healthcare workers, in surgical intensive care unit and wards, departmental meetings, outpatient clinic	Overview of the setting, environmental context and resource availability. Communication between healthcare workers and patients and carers. Captured the attitudes, roles and behaviours of stakeholders involved, with focus on IPC practices.
	Shadowing individuals		Trainee surgeons	Roles played by individuals with focus on IPC practices
			Medical Social workers	Communication with patients and carers.
	Focused observations		Patients and carers	Focus on individual patients. Highlighted IPC activities around the bed space and the involvement of carers.
Face-to-face interviews	Healthcare workers (HCW) interview	50 interviews (44 HCW 6 patients/carers)	Surgeons, trainee surgeons, anaesthetists, nurses, clinical pharmacists, medical social workers	Healthcare workers' perspective of roles related to IPC played by them, and by the patients and carers.
	Patients and carers		Patients who developed infections after undergoing surgery in the respective departments and their carers	Patient and carer experiences, roles and responsibility in patient care; with focus on IPC practices.
Documentary Analysis		9 documents	Guideline documents of World Health Organisation, Indian Council for Medical Research, National Centre for Disease Control, National Accreditation Board for Hospitals, Hospital guideline on patient and carer participation in healthcare decisions, hospital infection prevention and control (IPC) guideline	Supplementary analysis giving insight into current involvement of patients and carers in patient care recommended through guidelines and policies.

Table 2.

Theme	**Quotes**
Theme 1 (T1): Policy mandates, institutional practices, and HCWs expectations about carers involvement	**(T1 a)** *"We always tell the patient and the patient carer, they should wash their hand thoroughly before touching the patient, after using the washroom, and before food. All the carers should use face mask."* *-Interview, Medical Social Worker A* **(T1 b)** "…*they do have a role in infection control practice as long as you educate them that a chlorhexidine bath can go a long a way in preventing surgical site infection and postoperative infection... because they (carers) are in the 'more infected' parts of the hospital and as long as they ensure that they have good infection control practices, they will not be vectors that carry bugs from place to place, so yes, I feel it is an important role the patients and their carers can play in infection control practice."* *-Interview, Anaesthetist A* **(T1 c)** *"In the ward, they need all the bystanders of patients… in the ICU, the IPC care would be all done by the nursing staff, the number of staffs are higher and I think they are also well trained, so the infection control part would be at its best in the ICU, but it is not the same on the general wards."* *-Interview, Surgeon A* **(T1 d)** *"Every morning at 5:00 a.m. I take my shower. My daughter will give me bath with hot water and she wipes me dry and when I lie on my bed, the nurse will come, clean and apply the medicine. There is a hole there right, that they do the dressing for."* *-Interview, Patient A*
Theme 2 (T2): Carers Have Indispensable Presence at patient bedspace yet are invisible	**(T2 a)** *"I was always here [by patient bedside]. I have not left him even for a bit. Now it is 7 days since we are here and I am with him all the time."* *-Interview, Carer A* ***(T2 b)*** *The carer assisted patient to get up from bed, and held on to her while she walked. They came out of the cubicle and walked through the corridor for a while. The carer was observed not to be using a hand sanitizer while she came in contact with the patient.* *-Observation notes*

Theme	Quotes
	(T2 c) *"[*During IP stay at hospital*] my son would go from intensive care to work. Then when I was transferred to a ward, my younger son and his wife came. As they have no children, both of them came to the hospital and stayed as carers for two nights. After that, my two younger sisters came… they both stayed with me for another two days."* *-Interview, Patient B* **(T2 d)** *"He has many other complications like Parkinson's, [high] blood pressure, [high blood] sugar, heart problem, kidney, etc.; so there are risks involved in this surgery and they asked me to sign the consent form. Since I know everything, I signed the form and gave consent.* *-Interview, Carer B* **(T2 e)** *"Actually, I was not conscious at all throughout... The children did not tell me about my condition. The doctor told me, there is a small problem only in the test. That is all I knew. Only after the surgery was completed, I came to know about the complication. My children did not tell me anything even about the surgery… the doctor came and spoke to me but he did not mention anything about the surgery. Maybe my children must have told the doctor not to talk about the surgery as I get tensed up."* *-Interview, Patient A* **(T2 f)** *"My husband and sons took decisions regarding my treatment while in hospital. It is all their choice. They [*family*] won't ask me anything."* *-Interview, Patient B* **(T2 g)** *"I asked her if she had received any counselling during the day of the discharge. She said no one had come to see her... She assumed that since she is being discharged, the staff saw no issue with her and didn't feel the need to meet her. Her husband intervened and said that when he had gone to pay the bills, he was directed towards a counter for medication counselling. Here, he was told about the care to be taken, diet and about the medication prescribed and when to take them. The patient did not receive counselling but the carer was given one."* *-Observation notes* **(T2 h)** *"I was the one who was cleaning [the wound] but I could not see anything. One day he was wearing a blue colored shirt and that was wet. At that time my daughter was taking care since I had fever. I asked my daughter why his shirt is wet over there… It then got dry and there was a stain mark. So I had a doubt and opened the shirt to check and noticed the water was oozing out of a small needle sized hole on the lower part of the surgical wound. He has slight low vision and he didn't notice the wetness on his shirt. Then I called the hospital immediately."* *-Interview, Carer C*

Theme	Quotes
	(T2 i) *"I don't how the infection happened. I was in the hospital… We have to share the toilet with other patients. Also, here so many visitors come to see other patients. We can't control that right? But we can do so at home. My husband and children are saying that they are going to clean up the room and not allow any visitors for 2-3 months, but in the hospital can we follow all that? So many people come here."* *-Interview, Patient A* ***(T2 j)*** *"[*After discharge*], for two months, I was staying with my daughter. I and my husband were staying upstairs. Nobody would come to that floor, not even my children. My daughter would promptly bring our food and my husband was there to take care of me"* *-Interview, Patient B* **(T2 k)** *"We were actually careful. We used to use the hand rub every time we were approaching the room. We did not allow guests for many months. We took the decision because she has the colostomy bag and that itself is lot of infection so that may harm her more, right?"* *-Interview, Carer C* **(T2 l)** *"We did not hear any update from doctor. My daughter is also a doctor. She asked to find out about the culture report after the 4th day. I would ask them but they said it did not come yet"* *-Interview, Carer D*
Theme 3 (T3): Carer Education is Inconsistent	**(T3 a)** *"We did not receive any special instructions on dressing and IPC care after discharge. Actually I used to see how it was done, so I learned it myself and when they asked me whether I needed anything and I just said no. By that time I had learnt it."* *-Interview, Carer C* **(T3 b)** *The surgical trainee informed the carer that he should keep changing the tubes after going home. He then asked if he was taught how to do it. The carer started explaining what has to be done. The trainee intervened and warned him that his hands should be clean, properly washed before he did the procedure.* *-Observation notes* **(T3 c)** "*There is no education, per se. If they have stomas, then we have staff who go and train the carers on that. On a day-to-day basis, when we take rounds, we give them basic information, about their wounds there is no specific orientation"* *-Interview, Surgical trainee A*

Key findings and implications	Recommendations for future practice
Carer roles and responsibilities are not recognised in existing infection prevention and control guidelines and policies, despite their roles in patient care.	Greater awareness of different cultural norms in relation to carer roles in IPC policy and guidelines. Active engagement with and participation of carers by healthcare workers (HCWs) where they are present, able, and willing to contribute to patient care.
Where expectations are placed on carers these are often not supported by training or support for them to carry out their roles effectively.	Formal acknowledgement of carer roles in policy and guidelines. This needs to be supplemented by providing support and education to carers. This has the additional benefit of recognising the knowledge on patient care needs that carers bring, enhancing patient care and outcomes. However, consider unintended consequences.
There is a lack of effective communication tools for carers who may have different needs to HCWs or patients.	There needs to be a move towards communicating with carers about healthcare on platforms and in language that is accessible to them. Particularly providing information not only about hospital related care, but also post-discharge. Peer-led provision of information in this area needs to be explored.

Box 1 Key findings, their implications, and recommendations for future practice