Understanding the Role of the Informal Caregiver in Infection Prevention and Control in Hospitals in Vietnam: A Focused Ethnographic Study.

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Abstract

Background: In low- and middle-income countries, informal caregivers assume an expanded role in patient care, driven by cultural factors and human resource constraints. A comprehensive systematic review was undertaken to consolidate existing evidence concerning the distinct engagement of informal caregivers in patient care across low- and middle-income countries. This review highlighted a critical gap in understanding their pivotal yet inadequately explored contribution to infection prevention and control within hospital environments in these settings. Hospital-acquired infections pose a significant global healthcare challenge, disproportionately affecting low- and middle-income countries due to systemic challenges, including inadequate infrastructure and human resources. Given the significance of hospital-acquired infections, exploring the role of the informal caregiver in infection control is warranted.

Methods: This study employed focused ethnography involving informal caregivers and healthcare workers at a secondary-level acute public hospital in Hanoi, Vietnam. Data collection took place in adult inpatient departments over four intermittent weeks from August to December 2018. Purposive sampling using snowballing selected information-rich participants. Data collection methods included observation, semi-structured interviews with informal caregivers and healthcare workers, and a reflection diary to acknowledge researcher biases and ensure quality. Data analysis used Roper and Shapira's (2000) framework for thematic analysis, which was adapted for focused ethnography. Initially, the data was coded into broad categories, which were then refined into descriptive labels. Patterns were identified within these labels, forming themes relevant to the research question. A flexible approach allowed for theme identification through frequency, aligned with the research question. The World Health Organization's core components of the infection control model were then applied for further coding, refining the initial codes. Themes were iteratively reviewed to ensure alignment with participant experiences and research questions. Complex relationships between themes were identified and refined throughout the iterative process.

Results: Over four intermittent weeks, spanning four hospital departments (general medicine, neurosurgery, orthopaedics and the emergency room), 32 hours of participant observation and 25 participant interviews were conducted with informal caregivers and healthcare workers. Three themes were identified in the research. Firstly, the embedded role of informal caregivers in the healthcare ecosystem was highlighted, identifying a cadre of commercial caregivers and an increasing professionalisation of the informal caregiving role. The research further identified informal caregivers' acknowledgement of national health policy, cultural expectations, and reliance on their role but found their integration into the healthcare workforce remains incomplete. Secondly, informal caregivers as proxy healthcare workers in infection prevention and control highlighted their involvement in patient care tasks, many of which pose infection control risks. The research also revealed the formation of a community among informal caregivers, and their interaction with the hospital environment akin to a domestic space was noted. Lastly, navigating the duality of informal caregivers' role in infection prevention and control as both a challenge and an opportunity underscored disparities in infection prevention and control between healthcare workers and informal carers, revealing varying knowledge levels and blame-shifting tendencies among staff. Patients and carers are often uninformed of infection diagnoses, highlighting the need for improved education and consistency. Moreover, constraints such as hospital infrastructure hinder infection control measures, necessitating action to support informal carers and enhance healthcare settings.

Conclusion: The research underscores the crucial yet often overlooked role of informal caregivers in healthcare systems, particularly evident in low-income countries, emphasising the need to consider cultural-specific factors. It highlights the intricate interplay between culture and patient safety within the context of informal caregivers in hospitals, revealing various dimensions that influence caregivers' interactions and impact patient safety. Moreover, it identifies a lack of awareness among informal caregivers regarding their role in infection control, indicating the necessity for targeted education and training programmes tailored to them. The study also uncovers significant infrastructural, educational, and cultural barriers hindering the practical implementation of infection control measures by informal caregivers. It provides policy, practice, and research recommendations across infection control, emphasising the need for infection control training among informal caregivers, recognition of their role, resource allocation and understanding of their interactions in the hospital environment. Furthermore, it contributes to the existing body of knowledge by deepening our understanding of the role of informal caregivers in infection prevention and control. The findings carry implications for policy and practice, supporting tailored interventions to empower informal caregivers in their infection control roles.

Addressing the identified challenges and promoting collaboration between healthcare workers and informal caregivers can enhance patient safety and mitigate the risk of healthcare-associated infections in low- and middle-income countries. Lastly, while valuable insights have been provided, it is essential to acknowledge the research's limitations and the need for further research to build upon these findings and further advance our understanding of this important area.

Table of Contents

ABSTRACT I

LIST OF TABLES XI

LIST OF FIGURES...XII

ACKNOWLEDGEMENTS XIII

DECLARATION XV

1 INTRODUCTION 1

1.1 Why does the hospital environment matter for infection transmission? 2

1.2 Infection prevention and control 3

1.3 Motivation for this study 5

1.4 Vietnam's health system context 6

1.5 Infection prevention and control in low- and middle-income countries 11

1.6 Who provides patient care in low- and middle-income countries?.................................. 15

1.7 Gaps in research... 18

1.8 Purpose of the study aims and objectives and research question 19

1.9 The organisation of the thesis 20

2 A SYSTEMATIC REVIEW OF THE LITERATURE 22

2.1 Introduction 22

2.2 Review design 23

2.3 Formulating a review question........ 24

2.4 Comprehensive systematic search 24

2.5 Study selection and appraisal........ 26

2.6 Analysing and synthesising qualitative findings: Synthesis approach 38

2.7 Theme 1: The unwelcome but tolerated guest 41

2.8 Theme 2: Enduring personal sacrifice 46

2.9 Theme 3: Fulfilling familial obligations 49

2.10 Discussion of findings 52

2.11 Strengths and limitations 55

2.12 Conclusions 56

3 METHODOLOGY 57

3.1 Aims and objectives and research question 57

3.2 The constructivist paradigm 57

3.3 Rationale for a methodological approach 59

3.4 Choosing a qualitative methodology 60

3.5 Ethnography 61

3.6 Underlying systems thinking 63

3.7 Researcher as a data collection instrument 65

3.8 Selecting data collection approaches 66

4 METHODS 69

4.1 Introduction 69

4.2 Setting 69

4.3 Entering the field 69

4.4 Population 70

4.5 Sample 71

4.6 Recruitment 73

4.7 Data collection overview 74

4.8 Ethical approval 77

4.9 Quality and rigour 82

4.10 Data analysis 84

4.11 Conclusion 87

5 FINDINGS 88

5.1 An account of the study location 88

5.2 Data collected and study participant characteristics 92

5.3 Overview of themes 94

5.4 Theme 1: The embedded roles of informal caregivers in the healthcare ecosystem......... 95

5.5 Theme 2: Informal caregivers as proxy healthcare workers in infection prevention and control 101

5.6 Theme 3: Navigating the duality: Informal caregivers' role in infection prevention and control as a challenge and opportunity 111

5.7 Conclusion 119

6 DISCUSSION 120

6.1 Summary of findings 120

6.2 Discussion of findings 122

6.3 Informal caregivers as integral yet overlooked contributors in healthcare systems 124

6.4 The pervasive influence of culture on informal caregivers' roles in infection control..... 129

6.5 Strengths and limitations 137

6.6 Recommendations 145

6.8 Conclusion 149

7 7. APPENDICES 151

7.1 Appendix 1: Systematic review publication 151

7.2 Appendix 2: Systematic review PROSPERO protocol 161

7.3 Appendix 3: Detailed list of search terms 164

7.4 Appendix 4: Detailed Medline database search strategy 166

7.5 Appendix 5: Low- and middle-income countries as defined by the World Bank 168

7.6 Appendix 6: CASP Quality Appraisal Tool 170

7.7 Appendix 7: Data extraction tool 178

7.8 Appendix 8: Informational poster 185

7.9 Appendix 9: Informal caregiver participant booklet 186

7.10 Appendix 10: Healthcare worker participant booklet... 188

7.11 Appendix 11: Healthcare workers interview topic guide 190

7.12 Appendix 12: Informal caregiver interview topic guide 192

7.13 Appendix 13: Ethical approval form Lancaster University 194

7.14 Appendix 14: Presentation of proposal in Vietnam 211

7.15 Appendix 15: Observation written consent... 221

7.16 Appendix 16: Opt-out consent 223

7.17 Appendix 17: Interview written consent form... 224

7.18 Appendix 17: Researcher risk assessment 224

7.19 Appendix 19: Transcription examples 230

7.20 Appendix 20 : Vietnamese list of infection control terms.................................... 233

GLOSSARY...236

BIBLIOGRAPHY 238

List of Tables

Table 2.1: Database sources 25

Table 2.2: Inclusion/exclusion criteria 25

Table 2.3: Studies included in systematic review 28

Table 2.4: Themes 40

Table 3.1: Comparison between conventional and focused ethnographies 63

Table 4.1: Informal caregiver participant inclusion and exclusion criteria 70

Table 4.2: Healthcare worker participant inclusion and exclusion criteria 71

Table 5.1: Data collection and participant characteristics **...................................... 93**

Table 5.2: Findings overview 94

Table 5.3: Definition of direct and indirect patient care 102

Table 5.4: Observed patient care tasks performed by informal caregivers 102

Table 5.5: Infection prevention and control practices observed 114

Table 6.1 Recommendations 137

List of Figures

Figure 1.1: The World Health Organization’s core components of infection prevention and control 5

Figure 1.2: Health service delivery model in Vietnam 7

Figure 2.1: PRISMA flow diagram 40

Figure 4.1: The World Health Organization's health systems framework 86

Figure 5.1: Emergency department layout 89

Figure 5.2: General medical department layout 90

Figure 5.3: Neurosurgical department layout 91

Figure 5.4: Orthopaedic department layout 92

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Declaration

I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

1 Introduction

In this chapter, I introduce the background and context to studying the role of informal caregivers in infection prevention and control in a hospital in Vietnam, a low- and middle-income country. I explore hospitals' role in infection transmission and introduce the World Health Organization's global framework for infection prevention and control core components, aiming to reduce hospital-acquired infections. I examine additional challenges influencing infection prevention and control implementation in low- and middle-income countries. I discuss the informal health workforce as an essential cadre providing patient care in low- and middle-income countries and articulate the study's need, purpose, aims and significance, followed by an outline of subsequent chapters in the thesis.

This research investigates the infection prevention and control role of informal caregivers in hospitals within Vietnam, a low- and middle-income country. Infection prevention and control constitutes a clinical and public health speciality grounded in a pragmatic, evidence-based approach. This approach aims to safeguard patients and health workers in and visitors to healthcare facilities by averting avoidable infections, including those caused by antimicrobial-resistant pathogens acquired during healthcare service provision (WHO, 2020). Through a series of work practices, infection prevention and control can prevent hospital-acquired infections, infections occurring more than 48 hours after admission that are not present or incubating at admission (WHO, 2002).

Hospital-acquired infections are a global healthcare challenge and are the most frequently reported adverse patient event in hospitals, resulting in increased patient mortality, morbidity and significant costs to the health system (Aiken et al., 2013; Allegranzi et al., 2010; Allegranzi & Pittet, 2009; Pessoa-Silva et al., 2007; Tartari et al., 2021; Tomczyk et al., 2020). The burden of hospital-acquired infections is estimated at one in ten among patients in high-income countries and as high as five in ten among patients in low- and middle-income countries (Tomczyk et al., 2022). This disparity in prevalence is explained through health system challenges faced in low- and middle-income countries, including inadequate infrastructure, lack of human resources, lack of a systemic emphasis on infection prevention and control, lack of education around infection prevention and control, and the lack of dedicated personnel to manage infection prevention and control programmes (Hussein et al., 2011; Murni et al., 2013; Nejad et al., 2011).

A distinct phenomenon in low- and middle-income countries is the presence of informal caregivers in the hospital who provide direct patient care. The term ‘informal caregivers’ employed throughout this research aligns with the World Health Organization’s definitions of ‘caregivers’ and ‘informal assistance’, as defined in the glossary (WHO, 2004).

1.1 Why does the hospital environment matter for infection transmission?

Healthcare facilities are often the source of, or they amplify infectious disease outbreaks and are a bridge to the community, contributing to further transmission (Tomczyk et al., 2022). The COVID-19 pandemic emphasised the role hospitals play in the transmission of disease and the critical need to prevent disease transmission to ensure the safety of patients, visitors and health workers. A patient's risk of developing hospital-acquired infections increases in relation to the length of their hospital stay, surgical history, number of invasive devices present, admission to an intensive care unit and poor staffing levels in the hospital (Hussein et al., 2011; Murni et al., 2013; Pessoa-Silva et al., 2007). The dynamics of infection transmission in hospitals are associated with microorganisms acquired from another person in the hospital (cross-infection), the patient's own flora (endogenous infection), or the hospital environment itself. Transmission routes for hospital-acquired infections include direct contact, indirect contact and droplet, airborne, faecal-oral and vector-borne transmission. The transmission of hospital-acquired infections is associated with frequent patient contact, patient density, healthcare worker mobility, the hospital environment and infection control practices (Allegranzi & Pittet, 2009).

The immunocompromised, old, young, malnourished and those with underlying chronic diseases may have increased susceptibility to infections with opportunistic pathogens. Patients undergoing surgery, diagnostic and therapeutic procedures, and those with invasive devices have their innate barriers against infection compromised, potentially introducing or migrating pathogens to wound sites and tissue (WHO, 2002). Crowded hospital conditions, frequent transfers of patients across hospital units and a concentration of patients who are highly susceptible to infection in one area, such as neonatal intensive care, all provide multiple sources of infection and an opportunity for exposure to infection (WHO, 2002; 2018a). Antimicrobial treatments are widespread among hospitalised patients, which promotes the emergence of multidrug-resistant microorganisms. Infections caused by multidrug-resistant microorganisms can be more enduring, difficult to treat and necessitate a longer hospital stay, further increasing the opportunity for exposure to infection. The healthcare workers, nurses, doctors and allied and support staff who interact with patients present a risk to the patient and are themselves at risk of occupational acquisition of infection. Occupational transmission of disease has been heavily reported in the literature and ranges from serious enduring infections like HIV, Hepatitis B and Hepatitis C to transitory infection and COVID-19 (Rivett et al., 2020; Shields et al., 2020; Sondlane et al., 2016; Verkuijl & Middelkoop, 2016). Infection prevention and control aims to mitigate the risk of infection transmission in hospitals.

1.2 Infection prevention and control

Infection prevention and control is a pervasive concern in healthcare, applicable universally across contexts and settings, and relevant to all individuals within the hospital environment. Its overarching goal is to avert harm to patients and healthcare workers by diminishing the occurrence of hospital-acquired infections. This is achieved, in part, through behavioural modifications aimed at disrupting the transmission chain between microorganisms and individuals, involving interventions to alter various clinical practices (Allegranzi & Pittet, 2009). Evidence-based infection prevention and control interventions effectively prevent at least 50% of hospital-acquired infections (Umscheid et al., 2011). This involves hand hygiene, personal protective equipment use, standard precautions, transmission-based precautions, safe disposal of sharps and healthcare waste, and proper laundry and environmental cleaning (WHO, 2002). It further includes additional precautions according to the pathogen transmission route, including airborne, droplet and contact precautions. These additional precautions require more stringent and extensive personal protective equipment practices, patient isolation, ventilation and enhanced cleaning and decontamination practices.

1.2.1 The World Health Organization's core components

The World Health Organization has developed a core components framework for infection prevention and control, setting standards for their implementation in healthcare settings (see **Figure 1**). Widely acknowledged globally, this framework serves as a reference for constructing effective infection prevention and control programmes at national and health facility levels. Two tools are associated with this framework to measure progress: the Infection Prevention and Control Assessment Framework for facility-level implementation and the Infection Prevention and Control Assessment Tool at the national level, aiding countries in identifying gaps and guiding action planning. Implementing all the World Health Organization's recommendations on core components is essential for building effective programmes, leading to a significant reduction in hospital-acquired infections and antimicrobial resistance (Tomczyk et al., 2022; WHO, 2016).

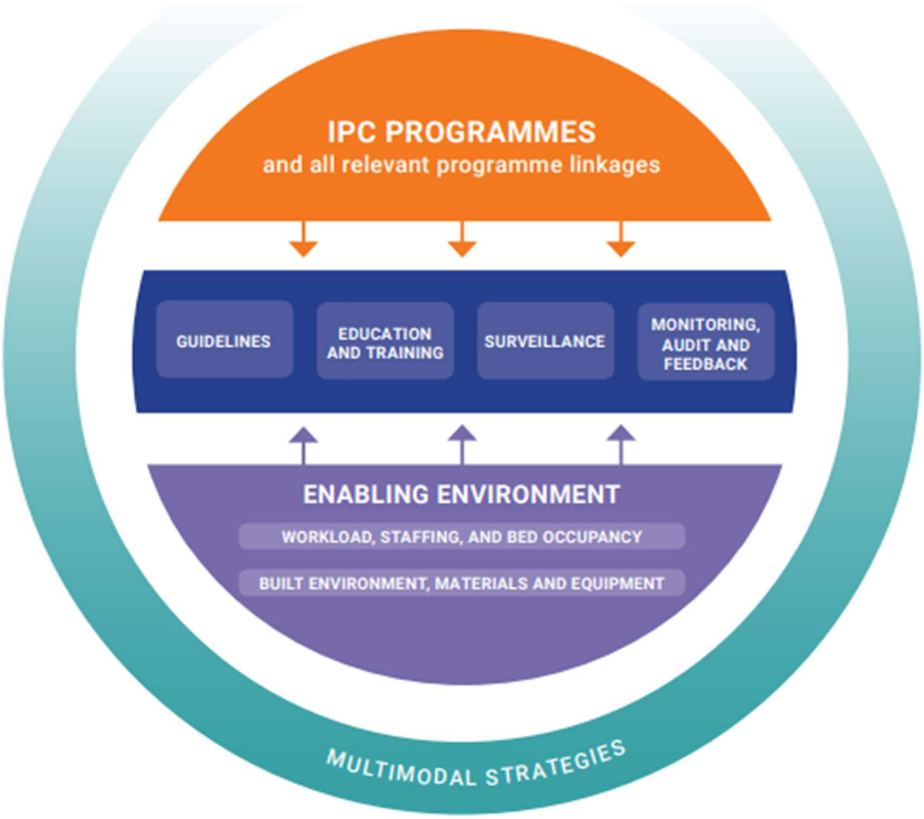

Figure 1.1: The World Health Organization's core components of infection prevention and control (WHO, 2019a, p.5)

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1.3 Motivation for this study

With over 15 years as a global infection control technical advisor in low-income countries, I have witnessed hospitals' persistent challenges in implementing infection control practices. A fundamentally overlooked observation I noted was that family members or guardians, not healthcare workers, provide direct patient care. This motivated my curiosity about emphasising healthcare workers in infection control policies, overlooking those providing direct care. Conducting research in Hanoi, Vietnam, during my role as an infection control advisor with an international NGO, I aimed to understand the infection control roles of informal caregivers in low- and middle-income countries. This study aligns with my experiences and addresses a critical gap in current approaches. To provide context to the research location, the following section discusses the organisation of the Vietnamese health system.

1.4 Vietnam’s health system context

Vietnam, located in Southeast Asia, is a lower-middle-income country with a population exceeding 97 million (World Bank, 2022b). Governed by the Communist Party of Vietnam, it underwent Đổi Mới economic reforms in 1986, transforming the country into a middle-income economy (Priwitzer, 2012). Despite progress, 6.7% (6.4 million) of the population lives below the poverty line (Yang, 2021). These economic changes have been accompanied by changes in health outcomes, including improvements in life expectancy and infant mortality (WHO, 2019b). A decline in communicable diseases has shifted the health landscape, with non-communicable diseases now dominating mortality causes (Nguyen & Trevisan, 2020). Cardiovascular disease, cancers, diabetes and road injuries now account for most mortality and morbidity in Vietnam (Nguyen & Trevisan, 2020).

Vietnam's health system operates across four administrative levels: central, provincial, district and commune (Le et al., 2010). Service delivery occurs at three major levels: primary (districts and communes), secondary (provinces) and tertiary (central government tertiary hospitals) (WHO, 2019b). It is a decentralised health system that has undergone several transformations to delineate responsibility and autonomy in recent years (WHO, 2019b). This reformed system is overseen by the Ministry of Health at the central level. Provinces and cities manage healthcare facilities and education programmes, while district and commune-level facilities offer basic medical care with preventative services (MOH, 2016; Nguyen & Cheng, 2017).

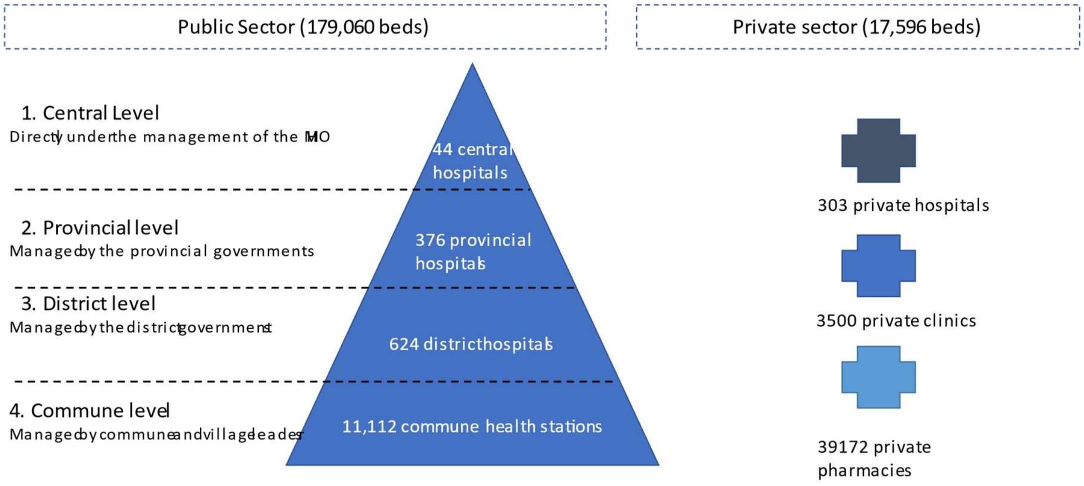


Figure 1.2: Health service delivery model in Vietnam (MOH, 2018; MOH, 2021)

Vietnam's hospital system is a mix of public and private hospitals, with 47 central-level hospitals, 419 provincial-level hospitals, 684 district hospitals and 182 private hospitals primarily located in urban areas (WHO, 2021). Since 2018, public hospitals, mainly at the provincial and central levels, have been operating autonomously and are no longer dependent on direct budget subsidies for their operating costs (WHO, 2021). 90.85% of Vietnam's population was covered by social health insurance in 2020, granting access to services across public hospitals (Oanh, 2021). Despite the high social insurance coverage, there is a disparity in the quality and accessibility of services between the tertiary-level service providers in major cities and the primary health services at grassroots levels (Oanh, 2021). Many patients bypass primary health centres and self-refer to hospitals as their first point of contact. These challenges with referral pathways and the introduction of user fees by newly autonomous hospitals to improve hospital financing have increased out-of-pocket payments for healthcare (Takashima et al., 2017).

Vietnam's hospitals face several challenges. They are notoriously overcrowded, with bed occupancy frequently over 100% (Salmon & McLaws, 2015). There are inadequate human resources for healthcare, and the ratio of patient load to doctor or nurse exceeds the global recommendations (Oanh, 2021). Vietnam has a significant shortage of healthcare professionals, with an estimated eight doctors and 1.432 nurses per 1,000 people (World Bank, 2020). Compounding these issues is the perceived insufficiency of health worker salaries, averaging $163 per month (Oanh, 2021). Similar to other countries, the distribution of health workers is concentrated in urban areas, with rural facilities being underserved.

1.4.1 Vietnam's infection control

Hospital-acquired infection surveillance is a core component of both facility and national infection prevention and control programmes worldwide (Coker et al., 2022). There is no national hospital-acquired infection surveillance system in Vietnam, and data on incidence is scarce (Phu et al., 2016). In 2016, the Vietnam Administration for Medical Services under the Ministry of Health, the US Center for Disease Control and the nongovernmental organisation PATH rolled out standardised bloodstream infection and urinary tract infection surveillance in select intensive care units at six hospitals, establishing an important foundation for a national hospital-acquired infection surveillance system for the future (Coker et al., 2022). Point prevalence studies conducted in the country have focused primarily on surgical site infection rates with a prevalence between 10-12% (Nguyen et al., 2001; Thu et al., 2005; Viet Hung et al., 2016). In comparison to the surgical site infection prevalence in other countries, USA (2.8%), China (4.5%), Australia (3%) and Korea (4.5%), Vietnam bears a higher burden of surgical site infections (Barie, 2002; Fan et al., 2014; Park et al., 2015). Prevalent infections reported in the Southeast Asia region, which includes Vietnam, include ventilator-associated pneumonia, central line-associated bloodstream infections, catheter-associated urinary tract infections and surgical site infections (Allegranzi et al., 2011; Ling et al., 2015; Nejad et al., 2011; Thu et al., 2005; Viet Hung et al., 2016; Wilson, 2015).

Multiple studies conducted in Vietnam have reported the prevalence of infections caused by gram-negative bacteria with high antimicrobial resistance rates (Peters et al., 2019; Phu et al., 2016; Thuy et al., 2018). In intensive care units, as many as 60% of Intensive Care Unit patients are colonised with antimicrobial-resistant organisms, with 23% developing a hospital-acquired infection (Thuy et al., 2018). In neonatal intensive care in Vietnam, a mortality rate of 31.8% after infection was found, associated with an increased risk of fatality for every additional resistance to an antibiotic class (Peters et al., 2019). Bloodstream infections were predominantly caused by antimicrobial-resistant pathogens associated with an overall case fatality rate of 28.9% (Dat et al., 2017). To address hospital-acquired infections, Vietnam implemented a National Action Plan on infection prevention and control between 2016 and 2020, establishing infection control systems at several hospitals (WHO, 2018b). The Ministry of Health also implemented a National Action Plan for Combatting Drug Resistance (2013-2020) (Chua et al., 2021). An analysis of this latter action plan found that it adopted a multi-sectoral approach, established a national governance structure for antimicrobial resistance and prioritised the production of generic drugs in the country (Chua et al., 2021). There has been no analysis of the progress and outcomes of implementing the infection control action plan.

During the COVID-19 pandemic, Vietnam initially excelled in containing and mitigating the virus's impact, receiving acclaim for minimising occupational infections. Despite its successes, Vietnam faced challenges in aligning its healthcare system with the World Health Organization's recommended core components of infection control. These challenges mirror common issues in low- and middle-income countries combating infectious diseases. Vietnam's pandemic experience emphasises the ongoing necessity to address these challenges and strengthen the resilience and preparedness of healthcare systems in low- and middle-income countries for effective responses to public health crises.

1.4.2 Vietnam’s Policy Landscape on Informal Caregivers in Healthcare

In Vietnam, the involvement of family members as informal caregivers in hospital care is deeply rooted in cultural practices. Despite limited formal national policies explicitly defining the role of these caregivers, specific regulations provide implicit support for their participation, acknowledging the role of family members in the care and recovery of patients. This framework reflects the country’s unique healthcare dynamics, shaped by resource constraints, high patient loads, and a cultural emphasis on familial responsibility in health settings.

Circular No. 07/2011/TT-BYT, issued by the Ministry of Health on January 26, 2011, addresses guidelines for hospital organization and operation, with an emphasis on patient-centered care. While this circular primarily outlines the responsibilities of healthcare providers, it implicitly promotes family involvement by highlighting the importance of “clear and frequent communication between medical staff and patients’ families.” This focus on communication creates space for family members to be more engaged, providing emotional support and assisting in basic care tasks where formal hospital resources may be limited (MOH, 2011).

On August 13, 2013, the Ministry of Health introduced Circular No. 23/2013/TT-BYT, which underscores patient safety in healthcare settings, specifically encouraging “active participation of patients and their families in ensuring safety during medical treatments.” This directive reinforces the notion that family members are not merely visitors but active participants in safeguarding the patient’s well-being, thus aligning with Vietnam’s cultural expectations of family involvement. This participation includes supporting daily patient needs, monitoring their condition, and serving as a crucial bridge between the patient and the healthcare team. By inviting family members to engage in patient safety, this circular acknowledges and reinforces their valuable role in patient support (MOH, 2013a).

Circular No. 19/2013/TT-BYT, released on July 12, 2013, focuses on quality improvement within healthcare establishments. It emphasizes that feedback from patients and families should be “a core component in assessing and improving healthcare quality,” positioning family members as key stakeholders in the evaluation and enhancement of service delivery. This provision not only encourages hospitals to solicit family feedback on medical services but also legitimizes the informal caregiver's voice in the hospital setting. This inclusion provides a structural acknowledgment of the contributions and insights of family caregivers regarding patient needs, potentially informing adjustments in care protocols to improve patient outcomes (MOH 2013b).

While national policies provide a broad framework, individual hospitals in Vietnam often implement specific regulations that directly facilitate family involvement in patient care. Such policies may authorize family members to assist with routine activities like feeding, personal hygiene, and basic monitoring, effectively integrating family support into the patient care model. These hospital-level protocols align with the expectations set forth in Circular No. 23/2013/TT-BYT and Circular No. 19/2013/TT-BYT, acknowledging the necessity of informal caregiving in managing high patient volumes and limited hospital staffing (MOH, 2011; MOH 2013a; MOH 2013b).

1.5 Infection prevention and control in low- and middle-income countries

Low- and middle-income countries bear a disproportionate burden of hospital-acquired infections and face additional resource, infrastructural and educational barriers in implementing adequate infection prevention measures. In low- and middle-income countries, achieving the World Health Organization's core infection prevention and control standards is particularly challenging. The first global survey on infection prevention and control in health facilities was published in 2022, providing an overview of infection prevention and control programme implementation in 4,440 healthcare facilities in 81 countries across all six World Health Organization regions and income levels (Tomczyk et al., 2022). There was a significantly lower infection prevention and control implementation level in low- and middle-income countries than in high-income countries. No low-income country surveyed met all the indicators for the minimum infection prevention and control requirements.

In low- and middle-income countries, infection prevention and control programmes are often underdeveloped or entirely absent and lack dedicated professionals and allocated budgets (Bardossy et al., 2016; Tomczyk et al., 2022). There is limited availability of infection prevention and control guidelines in low- and middle-income countries. Where guidelines are available, they are often adopted from high-income countries, unfit for the context, underutilised, rendered impracticable and rarely supported by implementation strategy or evaluated for compliance (Tartari et al., 2021; Tomczyk et al., 2022; Zimmerman et al., 2011).

In low- and middle-income countries, there is a lack of infection prevention and control education at the undergraduate, postgraduate and in-service levels (Chan et al., 2016; Darmstadt et al., 2005; Lazzari et al., 2004; Liu et al., 2014; Marjadi & McLaws, 2010; Mazumder et al., 2014; Sengupta et al., 2019; Tartari et al., 2021). Specialist training in infection prevention and control is often absent, and pathways for infection prevention and control as a clinical specialism are rare (Bardossy et al., 2016). Allied health personnel, including cleaning, security, catering and other support staff, may not receive infection prevention and control education upon hiring or during employment (Tartari et al., 2021; Tomczyk et al., 2022). The inaccessibility of infection prevention and control education due to it rarely being offered in local languages may contribute to this (Sengupta et al., 2019).

While high-income countries utilise hospital infection rates as performance indicators impacting budget allocations and patient outcomes, the incentive for surveillance is lacking in low- and middle-income countries. Limited resources, the absence of standardised case definitions and inadequate laboratory support further impede effective surveillance in these settings (McGreevey et al., 1997; Raza et al., 2004; Coker et al., 2022).

Monitoring, auditing and feedback, vital components of infection prevention and control, received low scores in low- and middle-income countries in the 2022 global survey by Tomczyk et al. This tool is crucial for increasing healthcare workers' awareness and prompting attitudinal changes and improvements in professional practice (Ivers et al., 2012). However, the absence of a systemic approach and a prevalent blame culture often make monitoring and feedback unwelcome (Sparke et al., 2020; van Buijtene & Foster, 2019).

Creating an enabling environment for infection prevention and control is fundamental to its implementation. This encompasses the built environment, staffing levels, bed occupancy and the availability of equipment and supplies. The literature extensively documents infrastructural challenges in low- and middle-income countries, such as limited access to hand hygiene stations, a scarcity of functional latrines and inconsistent power supply (Tomczyk et al., 2022). A limited health workforce, often exacerbated by outward migration and chronic underinvestment, poses a significant barrier to implementing infection prevention and control. All fifty-seven countries on the World Health Organization’s list of critical health worker shortages fall within low- and middle-income categories. Inadequate supplies further compound this challenge (Bardossy et al., 2016).

Multimodal strategies have proven remarkably effective in low- and middle-income countries to reduce hospital-acquired infections. For example, the World Health Organization's multimodal hand hygiene strategy has shown score improvements in the Hand Hygiene Self-Assessment Framework across numerous countries (Allegranzi et al., 2013b; An & Yang, 2020; Loftus et al., 2019). Multimodal strategies are emerging as a tool for resilience in the continuity of care during outbreaks and are adaptable during pandemics, even in low- and middle-income countries, ensuring the building of robust systems (Dai et al., 2021; Müller et al., 2022).

1.5.1 Contrasts in infection prevention and control between low- and middle-income countries and high-income countries

Infection prevention and control in low-and middle-income countries differs markedly from that in high-income countries (Raza et al., 2004). High-income countries primarily measure the value of infection prevention and control through cost savings for governments in care provision. However, in low- and middle-income countries, where almost 50% of healthcare financing comes from out-of-pocket payments, comparable financial value and cost savings from infection control investments are not demonstrable (Mills, 2014).

Infection prevention and control policies developed in high-income countries are often adopted for use in low-income countries; however, there are multiple limitations to their applicability in these contexts, hampering their success (Sparke et al., 2020). Infection prevention and control policies depend on the local characteristics of an infectious agent in terms of their transmission modes, incidence, prevalence and mortalities of disease they cause, their epidemiology and identification of risk factors and groups (Raza et al., 2004). Specific infection control policies such as waste disposal, antibiotic use, building design and post-exposure prophylaxis need to be adapted for a local context, mindful of these characteristics and more closely reflective of the operational circumstances of hospitals. Infection prevention and control policy, education, training and practice designed in resource-rich contexts address and target healthcare worker behaviour with the underpinning assumption that health workers will be the ones providing patient care (Allegranzi et al., 2010, 2011; Allegranzi & Pittet, 2009). Consequently, they may fail to account for the prevailing attributes of patient care in low- and middle-income countries where informal caregivers frequently deliver direct frontline patient care rather than the healthcare workers (Islam et al., 2014; Kipp et al., 2007; Sudhinaraset et al., 2013).

Given the process of the adoption of infection prevention and control knowledge, guidelines and practice are necessary for successful programme implementation (Zimmerman et al., 2011). Conceptual frameworks provide a lens through which to understand the process of the transfer and adoption of infection prevention and control evidence in practice (Donaldson et al., 2004). The successful use of conceptual frameworks to translate evidence into practice in various healthcare disciplines is well recognised in the literature (Zimmerman et al., 2011). For infection prevention and control, the conceptual frameworks most often adopted have been leadership change, a model for improvement, continuous quality improvement, behavioural theory and diffusion of innovation theory (Hall et al., 2007; Harnage, 2007; Leu, 1995; Misset et al., 2004; Pittet et al., 2000; Scales et al., 2011; Zimmerman et al., 2011, 2015). However, a dearth of literature describes this process in low- and middle-income countries. A study in Nepal has described a successful local adaptation of continuous quality improvement for hand hygiene, including educational presentations, simple posters and the introduction of infection control champions (Kong & Kong, 2013). The diffusion of innovation theory has been successfully adopted in Kiribati for infection prevention and control, emphasising the importance of involving the end user in the innovation process and the particular role of champions in supporting implementation (Zimmerman et al., 2015). Understanding the process for adopting infection prevention and control is essential in recognising end users' involvement so that it can be replicated elsewhere in low- and middle-income countries.

There is a gap in the literature describing the social, religious, spiritual and cultural influence on infection control practices (Sparke et al., 2020). Culture and religion influenced hand hygiene practices where alcohol hand sanitiser conflicted with prohibition among some religions such as Buddhism, Islam and Sikhism and hand gestures in educational material were varyingly interpreted (Allegranzi et al., 2009). There is a notable lack of information on these cultural dimensions of infection prevention and control in low- and middle-income countries, making translating these practices difficult (Bardossy et al., 2016; Sparke et al., 2020). Cultural factors also influence a preference for how infection prevention and control knowledge is handed down through verbal rather than written instruction. Marjadi and McLaws (2010) describe how empiric, non-scientific modifications often supersede evidence-based knowledge gained through professional training when patients demand inappropriate therapies or when these therapies are more culturally acceptable. This impacts the ability to design culturally sensitive, locally adapted solutions for infection prevention and control programmes in low- and middle-income countries (Sparke et al., 2020).

1.6 Who provides patient care in low- and middle-income countries?

Inadequate human resources for health are frequently cited as a major obstacle to delivering patient care in low- and middle-income countries, with more than fifty countries identified as having critical shortages of health workers (Mandeville et al., 2016; WHO, 2016a). Meeting global targets for the number of health workers per population is unrealistic for many countries where it would require more than a third of gross domestic product to meet the requirement (Bossert & Ono, 2010). Producing more health workers is an unsuitable strategy where the labour market demand is not matched. Several sub-Saharan African governments have invested in increasing health worker training while simultaneously observing high levels of unemployment among nurses and doctors due to the inability to employ extra health workers (McPake et al., 2013). In both high- and low-income countries, an informal health workforce often performs community-level healthcare. Several studies report the presence of an informal health workforce for the delivery of patient care in community settings in low- and middle-income countries with fewer reporting on hospital settings (Bjegovic-

Mikanovic et al., 2014; Cross & MacGregor, 2010; Olaniran et al., 2017; Omaswa, 2006; Sales et al., 2006; Sheikh et al., 2017; Sudhinaraset et al., 2013). The contribution of informal health workers is often excluded from analyses despite their essential role in bridging the gap between the number of existing health workers and global targets (George, 2007; Mandeville et al., 2016). Informal caregivers are often women, and their contribution is rendered invisible through gender-disaggregated health workforce data (Morgan et al., 2016).

In hospitals in low- and middle-income countries, informal caregivers provide the bulk of healthcare, especially among people experiencing poverty, and they generally stay onsite in the hospital throughout a patient's admission (Sudhinaraset et al., 2013). This informal workforce is referred to differently across the literature, and there is no consistent definition for 'informal caregiver', which includes family members and lay caregivers. This person has been alternately referred to as a 'patient guardian', 'family carer', 'informal carer', 'informal caregiver', 'lay health worker', 'informal provider', 'attendant', etc. (Basu et al., 2014; Olaniran et al., 2017; Sheikh et al., 2017; Sudhinaraset et al., 2013). This group's common characteristics are the absence of formal healthcare training, the lack of any registration or regulation for their role, no professional affiliation and the role is usually unpaid (Sudhinaraset et al., 2013). Where payment is received, it is sometimes as a gift in kind, such as a meal or undocumented cash from the patient, not from an institution (Sudhinaraset et al., 2013).

1.6.1 What do informal caregivers do in hospitals in low- and middle-income countries?

The available relevant literature indicates there is a significant reliance on informal caregivers in hospitals in low- and middle-income countries. In addition, there is evidence to support the informal caregiver occupying a role in patient care across the physical, emotional, advocacy and financial domains, and in filling a human resources gap. Across several studies, informal caregivers in low- and middle-income countries' hospitals assist with the basic activities of daily living of the patient, with washing, feeding, dressing, elimination, turning and oral care being most commonly mentioned (Aziato & Adejumo, 2015; Brown, 2011; Hadley & Roques, 2007; Hoffman et al., 2012a;

Islam et al., 2014b; Sakurai-Doi et al., 2014; Zaman, 2004a). In two separate studies, informal caregivers were involved in invasive clinical procedures to insert nasogastric tubes and urinary catheters (Hadley et al., 2007a; Sakurai-Doi et al., 2014). This presents a potential risk for hospital-acquired infection transmission. Informal caregivers assisted patients during drug administration and transport across the hospital for investigations (Amiresmaili & Emrani, 2018a; Aziato & Adejumo, 2015; Zaman, 2013). In addition, they had a role in maintaining the cleanliness of the patients' bedrooms and hospital environment (Islam et al., 2014; Söderbäck & Christensson, 2008). Numerous studies found that informal caregivers identified their role as a bridge between healthcare workers and patients (Hadley et al., 2007; Mwangi et al., 2008; Paget et al., 2016a; Streid et al., 2014; Urizzi & Corrêa, 2007). Informal caregivers had an active role in liaising with medical staff, often requesting patient medication, enquiring about upcoming investigations and serving to inform a healthcare worker about the patient's medical history (Hoffman et al., 2012; Nunley, 1998; Urizzi & Corrêa, 2007).

Supporting patients emotionally has been identified across a range of studies, with informal caregivers recognising their role in providing moral, religious and social support to patients throughout their hospital stay (Aziato & Adejumo, 2015; Brown, 2011; Islam et al., 2014; Nunley, 1998; Söderbäck & Christensson, 2008; Streid et al., 2014; Zaman, 2013). Informal caregivers have engaged in measures to reassure patients through listening, physical touch, expressing empathy and endeavouring to cheer a patient’s spirits. They have also handled the demanding behaviour of the patients (Jagannathan et al., 2014). Informal caregivers have identified a role in paying for costs associated with patient care, such as food for the patient, bedding and transport to the hospital (Brown, 2012; d’Alessandro, 2015; Hadley et al., 2007; Israëls et al., 2008; Söderbäck & Christensson, 2008). In addition, purchasing patient medications is a commonly mentioned role and burden of informal caregivers in low- and middle-income countries’ hospitals (Aziato & Adejumo, 2015; Grant et al., 2003; Zaman, 2004; Zaman, 2013). ‘Under-the-table’ payments were explicitly mentioned in studies in Bangladesh and Niger, where informal caregivers identified a role in paying health workers for patient treatment, paying hospital gatekeepers for more attentive care and paying fines to the cleaning staff for any breaches in hygiene (d'Alessandro, 2015a; Zaman, 2013).

1.6.2 Why do informal caregivers provide patient care in hospitals in low- and middle-income countries?

Among the multiple reasons why informal caregivers have provided patient care in low- and middle-income countries' hospitals, the prevailing perception has been that they are needed to fill a human resources gap due to a lack of available healthcare workers. This form of task shifting of health workers responsibilities to informal caregivers has been the norm across the literature (Bhattacharyya & Chopra, 2020; Brown, 2011; Sakurai-Doi et al., 2014; Söderbäck & Christensson, 2007). Additionally, cultural and societal factors underpin the need for informal caregiver presence in hospitals performing patient care tasks (Bradley et al., 2015; Islam et al., 2014; Sudhinaraset et al., 2013). In Bangladesh, informal caregivers were assigned undesirable hands-on patient care tasks such as urinary catheter insertion. This was to reduce the stigma associated with physical care in the Bangladeshi context and protect the integrity of the nurses' reputation in a country where nursing is considered by the public as comparable to commercial sex work (Hadley et al., 2007). In addition, societal norms indicated that patients were more comfortable with a family member performing personal care such as bathing and washing, and there was a general preference for family members to perform such tasks (Amiresmaili & Emrani, 2018; Sakurai-Doi et al., 2014). This was bolstered by the strong evidence of a sense of familial duty to care for family members in other studies (Amiresmaili & Emrani, 2018; Baker et al., 2014; Brown, 2011; Hoffman et al., 2012; Islam et al., 2014)

1.7 Gaps in research

The gap in evidence that this research seeks to address is the underrecognized role of informal caregivers in infection prevention and control (IPC) within hospitals in low- and middle-income countries (LMICs). The preceding text in Chapter 1 illustrates the breadth of infection control challenges in resource-constrained contexts and the substantial reliance on informal caregivers. It explores the diverse roles informal caregivers play in hospitals across these settings, emphasizing the cultural and practical drivers behind this phenomenon. However, while some studies touch upon the broader contributions of informal caregivers, few have directly assessed their infection prevention and control practices, and fewer still address the associated risks and complexities of infection control in these settings. Prior research has shown that informal caregivers often assist with personal hygiene, feeding, and patient transport within hospitals—tasks that inherently carry infection transmission risks. Yet, these studies typically lack a focused examination of how caregivers understand and manage their roles often overlooking the infection control implications of their caregiving tasks.

This gap is significant because informal caregivers in low and middle-income countries frequently work in close contact with patients, often with limited access to infection control training, protective equipment, or support. Their high-touch roles position them as both potential agents of infection transmission and key allies in reducing infection risks if adequately supported. Recognizing this dual potential, this research aims to examine informal caregivers' specific infection control practices, assess associated infection risks, and explore perceptions of both caregivers and healthcare workers on the caregiver's infection control role. This study aims to bridge a critical evidence gap by offering insights that could inform infection prevention and control adaptations in low and middle-income countries, ultimately contributing to a safer healthcare environment that acknowledges the roles and realities of all care providers in these settings.

1.8 Purpose of the study aims and objectives and research question

1.8.1 Aim

The aim of the study is to explore the role of informal caregivers in infection prevention and control in hospitals in low-middle-income countries.

1.8.2 Objectives

The objective is to understand the role of the informal caregiver in hospitals in low-income countries. The specific objectives are:

1. To determine what patient care practices informal caregivers perform in the hospital and the associated risk of infection control of these practices.
2. To determine any infection control practices informal caregivers engage in during the course of their caregiving practices.
3. To explore informal caregivers' perceptions of their role in infection control during the course of their caregiving practices.
4. To explore healthcare workers' perception of the role of the informal caregiver in infection prevention and control in the hospital.

1.8.3 Research question

How do informal caregivers experience their role in infection prevention and control in hospitals in Vietnam?

1.9 The organisation of the thesis

This thesis is organised across six chapters.

In Chapter 1, the Introduction, I have addressed the background, aims and significance of the study. It introduces the key concepts of informal caregivers and infection prevention and control, establishing the study parameters. Additionally, I identify a literature gap that this research aims to address and outline the overall structure of the thesis.

In Chapter 2, I present a systematic review of the literature, focusing on the role of informal caregivers in infection prevention and control within hospitals in low- and middle-income countries. This comprehensive review includes a critical appraisal of informal caregiver experiences. This review has been published in the Journal of Health Services Research Policy and is accessible online at doi: 10.1177/13558196221101968 (Hogan et al., 2022).

Chapter 3 is dedicated to discussing the methodological approaches employed in this study. It includes an epistemological discussion, situating the study within its research paradigm. I discuss the rationale behind methodological choices throughout the research process, emphasising the role of systems thinking. I also provide an outline of the choice of qualitative methodology, with a detailed discussion on focused ethnography.

Chapter 4 provides an outline of the ethnographic methodology utilised in the study. It covers aspects such as the study setting, ethical considerations and the sample description for this ethnographic investigation. In the chapter, I detail the data collection methods employed, including interviews and field observations and provide an overview of the data analysis and methods of ensuring rigour are also provided. Reflexive accounts are interwoven throughout the chapter to enhance transparency in the research design and conduct.

In Chapter 5, ‘Data Analysis’ I present the study findings, offering an in-depth exploration of the collected data.

In Chapter 6, the ‘Discussion’ chapter, I contextualise the findings within the broader research landscape and engage in a comprehensive discussion of the implications for policy and practice, concluding with an examination of the study's limitations and presenting overall conclusions.

2 A systematic review of the literature

The content in this chapter has been published in a peer-reviewed qualitative meta-synthesis on the experience of informal caregivers in providing patient care in hospitals in low- and middle-income countries (Hogan et al., 2022) (see Appendix 1 for the full text, which was published in the Journal of Health Services Research and Policy).

2.1 Introduction

In hospitals in low- and middle-income countries, informal caregivers often live onsite in the hospital throughout a patient's stay, performing patient care tasks and functioning as *ad hoc* healthcare providers (Basu et al., 2014; Brown, 2012; Islam et al., 2014; Kipp et al., 2007). This practice is attributed to acute shortages of healthcare workers (and cultural and social norms which deem it more appropriate for a family member to perform intimate patient care (Hadley et al., 2007; Hoffman et al., 2012; Horng et al., 2016). Relying on informal caregivers to provide patient care may have implications for the quality of patient care, impacting patient outcomes. Despite the commonplace presence of informal caregivers, research on their experience in hospitals is scarce. The available research on informal caregivers is primarily drawn from the quality of life and burden of caregivingsurveys or focused on caregiving in the community for chronic diseases and is frequently located in high-income countries (Amiresmaili & Emrani, 2018; Park et al., 2020). This meta-synthesis focused on reviewing qualitative research investigating informal caregivers' experience of providing patient care in hospitals in low- and middle-income countries to gain insights into and an understanding of their distinct perspectives. The term 'informal caregivers' used throughout this review aligns with the World Health Organization's definition as:

> *Any person without formal health training who is not employed by the hospital facility and is onsite in the capacity as "carer" or "guardian" of a person known to them who is admitted to the facility as a patient* (WHO, 2004, p.34).

This review is intended to be useful for ministries of health who make decisions regarding quality standards, health policymakers, hospital administrators, healthcare managers, healthcare providers and international organisations involved in hospital care (Chivers et al., 2010; Mays & Pope, 1995).

2.2 Review design

The specific review question to be addressed is '*How do informal caregivers experience their role in providing patient care in hospitals in low- and middle-income countries?*' The methods for conducting qualitative meta-synthesis have been described by Sandelowski and Barroso (2007), and this meta-synthesis closely follows their approach. This approach was chosen because it facilitates the generation of a holistic understanding, allowing for a nuanced exploration of how context influences experience and is designed to integrate diverse perspectives from different qualitative studies, which is advantageous when dealing with a wide range of methodologies, paradigms and perspectives (Bohren et al., 2014; France et al., 2015; Landers et al., 2012; Sandelowski et al., 1997; Seers, 2015; Toye et al., 2014). Qualitative meta-synthesis involves an element of iteration through a search, retrieval and validation approach that necessitates a trail of decisions to enable replication of the results (Grant & Booth, 2009; Sandelowski, 2000).

Other qualitative synthesis approaches were considered, including interpretative synthesis, meta-ethnography and thematic synthesis; however, their aim to develop concepts produces an aggregation of theory and integrates qualitative studies through summation and assimilation, which was less well aligned with the purpose of this review (Burnett, 2011; Dixon-Woods et al., 2006; Grant & Booth, 2009; Mays & Pope, 2000; Toye et al., 2014). The practical value of systematic qualitative synthesis lies in collating qualitative material for other researchers who would not have the capacity to locate, read and interpret all the material individually (Harden & Thomas, 2005)(see Appendix 2 for the protocol for this systematic review). The protocol registration on PROSPERO is number CRD42017082345.

2.3 Formulating a review question

The first step of Sandelowski and Barroso's six steps of qualitative meta-synthesis is formulating a review question that guides the selection and analysis of literature. The research question for this review was formulated based on the SPIDER Model, which is consistent with Sandelowsi and Barroso's approach (Carroll et al., 2011; Cooke et al., 2012).

- **Sample:** informal caregivers in low- and middle-income countries
- **Phenomenon of interest:** experience perspective, attitudes, views, beliefs and perspectives of informal caregivers engaged in care provision in hospitals in low- and middle-income countries
- **Design:** ethnography, phenomenology, grounded theory, all qualitative variations, interviews, observation, systematic reviews
- **Evaluation:** the experience of caregiving
- **Research type**: qualitative data

This meta synthesis addresses the review question: 'How do informal caregivers experience their role in providing patient care in hospitals in low- and middle-income countries?'

2.4 Comprehensive systematic search

The second step of the meta-analysis by Sandelowski and Barroso (2007) is a comprehensive search strategy to locate studies of the experiences of informal caregivers in hospitals in low- and middle-income countries (Grant & Booth, 2009). It involved conducting an exhaustive systematic literature search, iterative searches, hand-searching, backward and forward citation searching and 'Berry picking'. Berry picking involves selectively and strategically extracting specific concepts or findings from diverse studies to construct a nuanced and coherent synthesis (Nolbit and Hare, 1988). Relevant literature was identified through an electronic database search of MEDLINE, EMBASE, CINAHL, PubMed and PsycINFO (see **Table 2.1).**

Table 2.1: Database sources

Data Source	Date of Search	Rationale
Databases		
CINAHL	05/06/2021	Nursing care related to patient care provision
EMBASE	29/06/2021	Biomedical database review for related literature
MEDLINE	05/06/2021-20/06/2021	Check for existing published literature related to central topics
PROSPERO	05/06/2021	Check for existing systematic reviews on related topics
PsycINFO	06/06/2021	Check around a concept for the emotional burden of caregiving

To formulate a search strategy, the search terms were divided into five categories: informal caregivers, hospitals in low- and middle-income countries, patient care and personal experience (see Appendix 3 for a detailed list of search terms employed and Appendix 4 for a complete electronic search strategy of the MEDLINE database). These search results were read through for relevance by students and supervisors and applied to the inclusion and exclusion criteria for review. The inclusion and exclusion criteria are outlined in **Table 2.2**. (Eakle et al., 2015; France et al., 2015; Mays & Pope, 2000; Sandelowski, 2008). Consensus on the final list of articles to be included was sought from discussions with PhD supervisors (Attred, 2005).

Table 2.2: Inclusion/exclusion criteria

Parameters	Inclusion Criteria	Exclusion Criteria
Location	Low- and middle-income countries as defined by the World Bank list (see **Appendix 5**)	Non- Low- and middle-income countries
Setting	Hospitals in low and middle-income countries	Community or non-acute patient care settings
Language	Articles written in English	Non-English language studies

Time frame	All available	None
Population	Articles that focus on informal caregivers Substantive component of findings related to informal caregivers	Articles focused exclusively on healthcare workers in low- and middle-income countries Articles focused on home-based care Community-based informal caregivers
Outcome	Articles concerned with the practices of informal caregivers in providing patient care. Experiences, perspectives, attitudes, views and beliefs of informal caregivers in providing patient care.	None
Study type	Qualitative primary research/ Secondary sources, such as systematic reviews with findings focused on informal caregivers in LMIC hospital settings.	Quantitative research
	Articles which report on qualitative, mixed-methods	Books, opinion pieces

2.5 Study selection and appraisal

The third step of Sandelowski and Barroso's six steps of qualitative meta-synthesis is screening and selecting appropriate research articles (Sandelowski, 2000). Titles and abstracts were reviewed to exclude duplicates, the remaining articles full text was assessed, and those not meeting the inclusion criteria were excluded. Articles meeting the inclusion criteria were appraised using the Critical Appraisal Skills Programme (see

Appendix 6). This programme is widely used for quality appraisal of evidence to be synthesised to demonstrate rigour in the systematic review (Long et al., 2020). The purpose of the quality assessment was to ensure the review accurately identified the explicit elements of quality in qualitative research, avoided drawing unreliable conclusions and considered the degree of reflexivity of the researcher as a hallmark for quality in qualitative research (Britten et al., 2002; Campbell et al., 2011; Cobb & Hagemaster, 1987; Harden & Thomas, 2005; Mays & Pope, 1995b, 2000). The appraisal was not intended to be a tool for the exclusion of articles as research participants' perspectives can be accurately represented even with low-quality articles, and research findings may still be relevant (Harden & Thomas, 2005; Sandelowski, 2008). The final list of included articles is in **Table 2.3**.

Table 2.3: Articles included in systematic review

Author/ Year Country	Aim	Qualitative approach	Participants	Data collection	Analysis approach	Findings	Quality appraisal
Aziato et al. (2014) Ghana	Explore psychosocial factors influencing caregivers during the care of surgical patients	Exploratory qualitative design	12 caregivers 1 key informant	Interviews	Thematic validation	Faith, fear, relief, empathy, commitment and inadequate knowledge influenced the caregiver experience	Good
Amiresmaili (2018) Iran	Show opportunities and threats of informal carers in hospital	Phenomenology	22 caregivers 9 nurses	Semi-structured interviews	Thematic analysis	Caregivers providing various types of patient support should be included as part of the health system and supported to do so	Good
Bhattacharyya & Chatterjee (2019) India	Explore the experience of family caregivers of hospitalised older people	Qualitative – not specified	54 caregivers	Interviews and field observations	Thematic analysis	The hospital environment was difficult for caregivers and impacted their health	Acceptable

	in Kolkata, India					financially and socially.	
Brown et al. (2011) **Kenya**	Explore the relationship between the (medical) hospital and (domestic) spaces and how the home is (re)made and inverted within the hospital wards and caregivers.	Ethnography	Not specified	Observation	Not specified	The organisation of space within the hospital meant patients were subject to two divergent care models – medical and domestic.	Low
d'Alessandro (2015). **Niger**	To describe the practices and issues of medical and personal care and hospital hygiene and compare to infection prevention and control standards	Anthropology	8 caregivers 56 nurses, doctors and cleaners	Interviews and field observations	Thematic analysis	Personal care activities are performed by untrained family members and are characterised by an unhygienic domestic space.	Low

Eslami et al. (2018) **Iran**	To explain the perspectives and experiences among caregivers of the patients undergoing haemodialysis in Iran	A descriptive exploratory qualitative design	25 family caregivers	Interviews and field observations	Thematic analysis	Caregivers face challenges such as the heavy burden of care, tension in care and emotional exhaustion.	Good
Grant (2003) **Kenya**	Discuss patient and caregiver end-of-life experiences among those with cancer or AIDS	Qualitative – not specified	32 patients and their caregivers	Interviews	Thematic analysis	Caregivers had an important role in meeting dying patients' physical, emotional, social, spiritual and financial needs.	Acceptable
Hadley et al. (2007) **Bangladesh**	Factors that influence nurses' behaviour in the provision of 'hands-on' care in hospital nurses' perception	Mixed methods	18 key informants- caregivers, health workers, patients	SS interviews, focus groups	Thematic analysis	Caregivers became nurse surrogates to perform patient care when nurses were unwilling to.	Good

Hoffman et al. (2014) Malawi	To characterise the caregiver population and explore their role in the health system of a hospital	Mixed methods	73 participants,60 caregivers, 13 hospital staff	Interviews, semi-qualitative survey	Thematic analysis	Caregivers performed various patient care tasks, had little support or respect in the hospital and had conflicts with hospital staff.	Good
Islam et al. (2014) Bangladesh	Explore family caregivers' perceptions and practices related to disease transmission in hospitals.	Ethnographic	12 caregivers	Observation	Thematic analysis	Caregivers performed multiple patient care tasks without appropriate infection control practices and were potentially at risk of disease.	Good
Israel et al. (2008) Malawi	Gain insight into the guardians' perspective on cancer treatment, especially concerning	Qualitative – not specified	25 caregivers	Interviews, focus groups	Grounded framework approach	Caregivers had multiple concerns about cancer diagnosis; it caused fear and imposed hardship on	Acceptable

	factors which could influence abandonment of treatment					them financially.	
Jagannathan et al.(2011) India	To explore the needs of caregivers of in-patients with schizophrenia in India.	Qualitative – not specified	30 caregivers	Focus Groups	Thematic analysis	Caregivers had a range of unmet needs, including education about schizophrenia and their health.	Acceptable
Makoae (2009) Lesotho	Caregivers' experiences with the bodily care of AIDS patients before antiretroviral therapies were available	Phenomenology	21 caregivers	Interviews	Phenomenological approach	Caregivers experienced sympathy, pain and stress in performing care	Acceptable
Mwangi et al. (2008) Tanzania	Experience and perceptions of paediatric in-patient care among	Qualitative – not specified	261 mother caregivers	Interviews	Thematic analysis	Mother caregivers experienced the hospital environment as unsupportive	Acceptable

	mother caregivers					and had conflicts with health workers.	
Oyegbile & Brysiewicz (2017) Nigeria	Experiences of family caregivers providing care for patients living with End-Stage Renal Disease in Nigeria	Qualitative descriptive study	15 caregivers	Interviews	Thematic analysis	Caregiving imposed a burden on caregivers of patients diagnosed with end-stage renal disease.	Good
Olwit et al. (2015) Uganda	Explore chronic sorrow as an expression of grief as seen among the caregivers of patients diagnosed with schizophrenia in Butabika Mental Hospital in Uganda	Descriptive qualitative design	22 caregivers	Interviews and focus groups	Content analysis	Caregivers felt chronic sorrow, stress and burden from their role. They used various coping strategies, mostly relying on internal strategies. r	Acceptable
Paget et al. (2016) Malawi	Explore the perspectives and	Exploratory, qualitative	6 caregivers from the in-patient setting	Interviews, focus groups	Thematic analysis	Caregivers of children with neurodisability	Good

	experiences of caregivers of children with disabilities from acquired brain injury in hospital settings					suffer the burden of care, opportunity costs, stigma and multiple barriers to accessing care.	
Park et al. (2020) Bangladesh/ Indonesia (S. Korea excluded)	Examine whether the role of patients' families has been accounted for in the infection prevention and control guidelines and policy	Systematic Review	Key informants and policy documents	Systematic search	Thematic analysis not specified	Healthcare workers are the primary actors in providing care in acute healthcare settings relevant infection control policy addressing family members involvement in care was identified in Bangladesh and Indonesia.	Good
Pesantes et al. (2017)	Characterise the impact of	Qualitative – not specified	12 caregivers	Interviews	Thematic analysis	Participants experienced	Good

Peru	post-stroke care among informal caregivers in a hospital setting					emotional stress, depressive symptoms and financial hardship as a result of caregiving.	
Söderbäck, & Christensso (2007). Mozambique	Describe nurses’ beliefs and practices regarding family involvement in the care of hospitalised children in Mozambique	Ethnographic	36 nurses	Interviews and field observations	Qualitative content analysis	Nurses perceived that caregivers should assist with patient care because of staff shortages. Nurses identified their role in educating and protecting caregivers and identified conflict.	Acceptable
Streid et al. (2014) Uganda, South Africa	Expand understanding of caregiver burden in Africa. Caregivers’	Qualitative- not specified	37 caregivers	Interviews *Stress Process Model	Thematic analysis	Caregivers’ stressors were daily patient care, emotional, financial, social	Good

	primary stressors related to day-to-day patient care.					isolation and familial responsibilities.	
Urizzi & Corrêa (2007) Brazil	Experience concerning family members of patients in the Intensive Care Unit	Phenomenology	17 caregivers	Family interviews	Thematic analysis	The experiences of the relatives of Intensive Care Unit hospitalised patients were painful and fearful, negatively impacting the family and causing mortality.	Good
Zaman (2004) Bangladesh	In hospital culture in the context of Bangladeshi society, family members were engaged in nursing and provide various kinds of support to	Ethnography	Not specified	Observation and interviews	Descriptive – not specified	Caregivers provided nursing care to patients and paid bribes to ward staff for daily necessities.	Low

	their hospitalised relatives.						
Zaman. (2013). Bangladesh	Explores the experiences of family members who had kin in the hospital	Ethnography	Not specified	Observation and interviews	Descriptive – not specified	Family members are an integral part of the informal organisation of the Bangladeshi hospital performing patient care.	Acceptable

2.6 Analysing and synthesising qualitative findings: Synthesis approach

Sandelowski and Barroso's fourth step of qualitative meta-synthesis involves analysing and synthesising qualitative findings (Sandelowski & Barroso, 2007). A thematic approach to the synthesis of included qualitative articles guided the analysis process. Thematic analysis) is a means of analysing and reporting patterns identified within and across data sets (Boyatzis, 1998). It can be used within both essentialist and constructionist paradigms, and a central benefit of this approach is its flexibility, which allows for an initial exploration of key emerging themes (Suri & Clarke, 2009; Thomas & Harden, 2008). It can provide insights into the experiences of individuals and the factors that influence their actions, adding to our holistic understanding of informal caregivers (France et al., 2015; Mays & Pope, 2000; Sword et al., 2009). The fifth step of Sandelowski and Barroso's qualitative meta-synthesis is maintaining quality control of the synthesis output. For consistent data to be extracted for this systematic review, a data extraction tool was developed (see Appendix 7). This extraction tool was adapted from the National Institute of Clinical Excellence's (NICE) qualitative data extraction tool (NICE, 2007). The domains of study setting, objectives, design, data collection and analysis, methods and themes were extracted from the primary research articles.

Given the exploratory nature of this systematic review, 'findings' were understood to be 'key concepts' arising from the research findings and also derived from various other sections of the publication (Campbell et al., 2011; Sandelowski, 2008). Relevant information included all data related to informal caregivers' experiences, perspectives, attitudes, views, beliefs and practices regarding hospital patient care provision. The inclusion of Park et al.'s (2020) systematic review in this meta-synthesis was justified due to its alignment with the inclusion criteria and synthesized insights into systemic gaps in infection control policies, particularly the exclusion of caregivers from formal strategies, offering a critical perspective on cultural and policy influences. The study was treated as a relevant secondary source, with data extraction focused solely on findings about informal caregivers, ensuring alignment with the meta-synthesis's qualitative focus. Any unrelated content, such as policy data from high-income settings, was excluded and there was no duplication in the systematic review with any of the primary original sources included.

The data was coded and organised hierarchically into 'coding trees' according to emergent concepts and their relationship to one another. The codes generated were not predefined and faced continual refinement, analysis and critical reflection to check their validity (Boyatzis, 1998; Carroll et al., 2013). Codes or 'labels' attached to the data highlight points of interest in this research and facilitate the identification of conceptual relationships between codes (Sandelowski, 2000; Tong et al., 2012). Through constant comparison and repeated examination of data, final themes were isolated across the articles and used to formulate synthesised findings. Consensus on each step was agreed between the student researcher and the PhD supervisors.

2.6.1 Findings

The final sixth step of Sandelowski and Barroso's qualitative meta-synthesis is presenting the findings (Sandelowski, 2000). One hundred thirty-two citations went through inclusion and exclusion criteria, and the final number of citations obtained from all combined strategies was 24. The final study selection is represented in **Figure 2.1**.

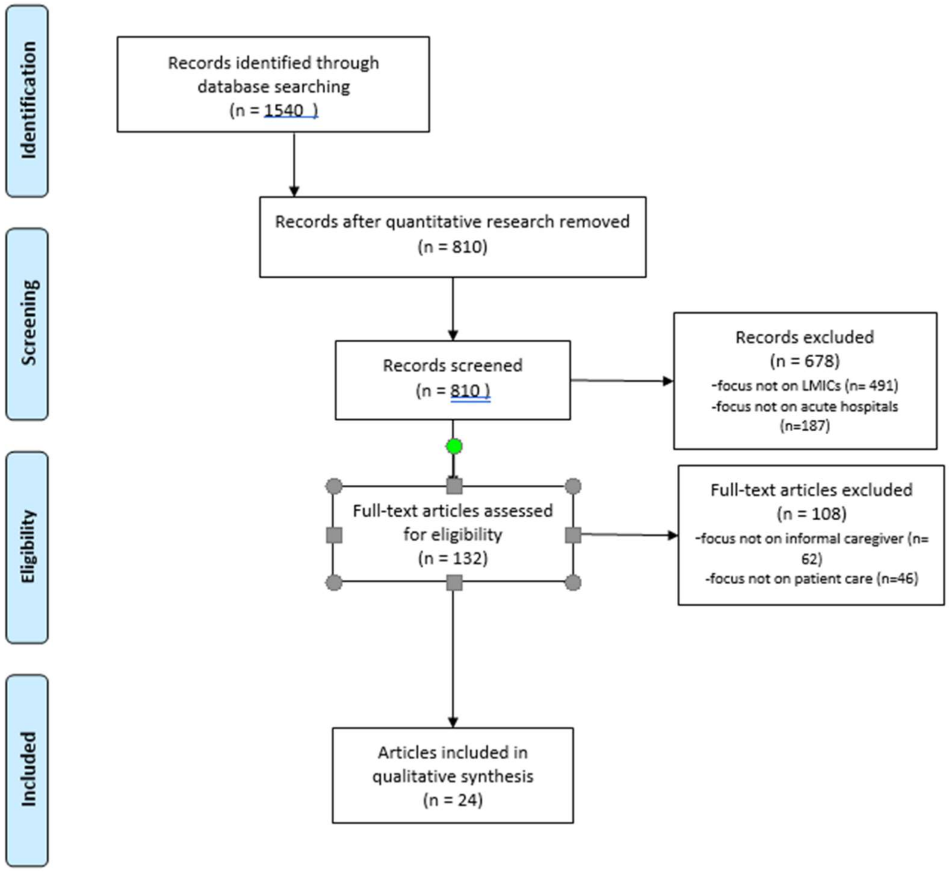


Figure 2.1: PRISMA flow diagram

The articles included in the review are summarised in **Table 3** below. Articles retrieved were conducted from a variety of geographical locations; 12 from sub-Saharan Africa (Kenya, Uganda, Ghana, Niger, Malawi, Tanzania, Lesotho, Nigeria, Mozambique*),* five from Bangladesh, two from India, two from Iran, one from Brazil and one from Peru. The review's findings led to the construction of three overarching themes*:* 1. The unwelcome but tolerated guest; 2. Enduring personal sacrifice, and 3. Fulfilling familial obligations. These themes are shown in

Table 2.4.

Table 2.4: Themes

Theme	Sub-theme
The unwelcome but tolerated guest	▪ Little accommodation made for the presence of the informal caregiver ▪ Tolerated out of necessity ▪ Undervalued for their contribution
Enduring personal sacrifice	▪ Effects on the health of the informal caregiver ▪ Sacrificed lives and futures ▪ Bearing the cost of caregiving
Fulfilling familial obligations	▪ Willingly fulfilling a perceived duty ▪ Adaptation to the role

2.7 Theme 1: The unwelcome but tolerated guest

This theme reflects the finding that for many informal caregivers, being in the hospital meant feeling marginalised by the hospital as there was little accommodation made for them. They perceived that they were undervalued for their contribution yet tolerated out of necessity for cultural and workload reasons. They felt that being an informal caregiver resulted in stereotyping of their knowledge and ability to care for the patient, which diminished their sense of power and autonomy in the hospital environment.

2.7.1 Little accommodation made for the informal caregiver

All 24 articles identified that the hospital environment was ill-equipped to accommodate informal caregivers. There was a lack of access to bathrooms, showers, potable water and rudimentary cooking facilities available for use by informal caregivers (Bhattacharyya & Chopra, 2020; Eslami et al., 2018; Hoffman et al., 2012; Islam et al., 2014; Mwangi et al., 2008). Frequently, informal caregivers shared beds with patients or slept on the ground outside the hospital (Brown, 2012; Grant et al., 2003; Hoffman et al., 2012; Israëls et al., 2008; Olwit et al., 2015; Streid et al., 2014). Some informal caregivers reported that hospital conditions prevented people from seeking timely hospital care. As expressed by one informal caregiver in India, '*Nobody would stay here unless compelled to'* (Bhattacharyya & Chopra, 2020, p89).

This was especially problematic for female caregivers who were predominant, which is consistent with the cultural norms of caring roles (Brown, 2012a; Hoffman et al., 2012b; Israëls et al., 2008a; Jagannathan et al., 2011). The hospital environment became a space where domestic and medical boundaries overlapped due to the often-extended nature of informal caregivers' stays in the hospital:

> *All around were signs of home, family, and faith. Family members frequently outnumbered patients on the wards. The trappings of home surrounded hospital beds: food, plastic basins, blankets, clothes, and bibles* (Brown, 2012a).

This contributed to an unhygienic space, which was a source of concern among informal caregivers (Bhattacharyya & Chopra, 2020; Hoffman et al., 2012; Oyeyemi et al., 2020). Bathrooms were often reported to be contaminated with excrement and generally unhygienic even when their use had to be paid for (Bhattacharyya & Chopra, 2020; Mwangi et al., 2008; Oyeyemi et al., 2020). The unhygienic conditions were met with resentment among hospital workers; one noted:

> *After a hundred relatives have left the ward, the floor looks like a wasteland. It is not surprising, therefore, that the ward cleaners always fight with them. While sweeping up the banana peels, nutshells, and empty chip bags, a cleaner told me, "See what these barbars (barbarians) have done. If you go to the toilet, you will see what they have done there; these stupid attendants of the patients come from the village and do not know how to use a toilet* (Zaman, 2004, p. 2030).

Hygiene supplies were generally absent in the patient ward, and materials such as gloves and cotton wool were not reliably available (Brown, 2012a; Hoffman et al., 2012b; Islam et al., 2014c). Informal caregivers reported having little access to soap for handwashing, even when cleaning up a patient's urine and felt hampered in providing quality patient care due to these limitations (d'Alessandro, 2015b). Informal caregivers often used their sharis and personal cloths to clean the patient (Islam et al., 2014c). The literature also addressed the increased risk of disease transmission through the work performed by informal caregivers and their lack of access to infection prevention measures (Islam et al., 2014c; Park et al., 2020). Many healthcare workers identified associated infection control risks due to these conditions, with an Iranian doctor noting:

> *Some Informal caregivers sleep on the ground next to their patients. It results in transfer of infections to themselves and others* (Amiresmaili & Emrani, 2018, p. 884).

Islam et al. (2014) reported that informal caregivers had some, albeit limited, understanding of disease transmission, describing direct contact with contaminated surfaces and waterborne disease as major modes of transmission. This limited understanding was exemplified by a caregiver in Kenya refusing to wear gloves when cleaning blood, '*She is my daughter, what can she give me?'* (Brown, 2012, p. 22).

No research identified if an informal caregiver had been infected with a hospital-acquired infection through their activities (Park et al., 2020).

2.7.2 Tolerated out of necessity

The literature identified there was an implicit reliance on informal caregivers to provide patient care and despite protestations about their presence, they were essential (Islam et al., 2014c; Makoae, 2009; Park et al., 2020; Söderbäck & Christensson, 2007b). An informal caregiver in a Ghanaian study noted:

> *But of late, caring is not the same. Some of the basic things that nurses should do, they are looking up to the patient's family to do it (key informant)* (Aziato & Adejumo, 2014, p. 7).

Sociocultural norms were a decisive factor in determining the informal caregivers' necessity. In some social contexts, personal and intimate care of patients was viewed as degrading to nurses (Hadley et al., 2007b; Islam et al., 2014c). In some Islamic cultures, physical contact between females and non-family members was prohibited, which interfered with healthcare workers' willingness to engage in patient interaction (Hadley et al., 2007b; Islam et al., 2014c). Implied here is a reliance on informal caregivers to perform nurse functions rooted in cultural norms. In Bangladesh, societal norms around nurses working night duty carried a cultural stigma of being associated with night-time commercial sex work, consequently reducing nurses' 'bride market' value (Islam et al., 2014c). To reduce the stigma associated with the nursing profession, nurses distanced themselves from patients, and patient relatives became nurse surrogates to carry out their work (Hadley et al., 2007b; Park et al., 2020). One informal caregiver articulated her experience:

> *I think nurses feel they are superior to poor patients and their carers. They don't like to associate with us because we are poor and dirty. They maintain a distance from these jobs in case their white dress might become dirty*(Hadley et al., 2007, p. 1171).

Informal caregivers who felt obliged to perform personal care tasks reported a similar culturally rooted sense of stigma and shame in their role:

> *In my culture, children are forbidden from seeing the nakedness of their parents…. But if I do not provide care for her, who else will? I am afraid for my life because of the repercussions of the taboo on me* (Family caregiver 02) (Oyegbile & Brysiewicz, 2017a, p. 2629).

In several articles, informal caregivers perceived healthcare workers as strict, uncaring and unwilling to do routine patient care. They rationalised their role as de facto nurses, performing functions that nurses were unwilling to do (Brown, 2012a; Hadley et al., 2007b; Islam et al., 2014c):

> *They [nurses] think as an educated person these tasks should not be their work, nor should they serve or give personal care to uneducated or poorly educated people*. (Patients carer, government hospital, age group 25–30) (Hadley et al., 2007, p.1171)

2.7.3 Undervalued for their contribution

Informal caregivers felt frustrated as they perceived that healthcare workers did not recognise their contribution to patient care (Eslami et al., 2018; Jagannathan et al., 2011; Streid et al., 2014b). They expressed a desire for a family-centred approach to care where they would be active participants in decisions but felt disempowered to approach this with health workers who often stereotyped them as incompetent (Bhattacharyya & Chopra Chatterjee, 2020b; Israëls et al., 2008a). Some informal caregivers felt reluctant to ask the nurses and doctors questions because they feared it would result in a reprimand (Israëls et al., 2008a). As noted in one Malawian study:

> *It is difficult for us to explain the patient's problem to the nurses, for example, you can tell the nurse the patient's problem, and she will answer, 'you do not listen! Wait for the doctor and tell him', this discourages us to ask anything* (Mother, Hosp. 1) (Mwangi et al., 2008, p.808).

In general, informal caregivers were more likely to criticise nurses than doctors' attitudes towards them, which may be indicative of more frequent interactions with nurses and maintaining the perceived higher status of medical doctors (Mwangi et al., 2008b; Urizzi & Corrêa, 2007). The lack of power of informal caregivers and their subservience to the authority of health workers within the hospital environment was prominently highlighted (Brown, 2012a; Hoffman et al., 2012b; Makoae, 2009). Informal caregivers frequently expressed a desire to feel less marginalised by the health system in their role:

> *I just sit here like a robot. Nurses asked me to buy items that my mother needed. They never told me why she needed them. They ordered me to pay for dialysis, laboratory investigations and other things. I don't like it when I do not know the reason behind my actions. I am sad to see myself as a fool being tossed around* (Family caregiver 03) (Oyegbile et al., 2017, p.2627).

Informal caregivers felt they had value to add to the patient care, which health workers did not recognise, and were stereotyped as poor and uneducated (Park et al., 2020; Streid et al., 2014b). The assumptions of informal caregivers' ignorance by healthcare workers may restrict an understanding of the real and complex reasons for behaviours while reinforcing a hierarchy based on possession of technical knowledge (Israëls et al., 2008a; Söderbäck & Christensson, 2007b). Healthcare workers frequently perceived that informal caregivers did not understand patient care and conducted unsafe practices, such as combining pharmaceuticals with local traditional medicine (Mwangi et al., 2008b). Some doctors noted that relatives did not understand the instructions about a patient's drug dosage or recommended exercise (Zaman, 2004a). Informal caregivers in a Malawian study worried that drawing blood (frequently) would weaken their child, especially when they did not understand why it was necessary (Israëls et al., 2008a). According to one Iranian healthcare worker:

> *Informal caregivers interfere in nursing activities; some of them have incomplete information and want to use it* (Amiresmaili & Emrani., 2018, p.883).

Healthcare workers wanted to educate informal caregivers but identified a lack of time as a barrier to providing education to individual informal caregivers (Soderback & Christensson, 2007). Healthcare workers believed they had a role in shielding family members from involvement in traumatic patient care activities such as phlebotomy, injections, or cerebrospinal fluid draws (Söderbäck & Christensson, 2007b; Urizzi & Corrêa, 2007). Some healthcare workers were also reluctant to tell informal caregivers about a patient's poor prognosis, thinking that they would then lose hope, abscond and try traditional medicine (Israëls et al., 2008a).

2.8 Theme 2: Enduring personal sacrifice

This theme reflects the finding that being in the hospital imposed significant personal sacrifice for many informal caregivers. Their caregiving role in the hospital negatively impacted their physical, emotional and social well-being. The impact of the caregiving experience was not confined to the hospital boundaries; rather, relationships and job prospects outside the hospital also suffered. The informal caregivers assumed the financial burden accompanying the caregiving role, which encompassed various costs.

2.8.1 Effects on the health of the informal caregiver

Informal caregivers experienced physical injuries associated with caregiving, including hip pain and back problems from lifting patients (Pesantes et al., 2017). They also faced barriers in accessing nutrition and caring for their personal health when in the hospital (Bhattacharyya & Chatterjee, 2019). Caregivers described day-to-day care as ‘exhausting’, frequently experiencing fatigue and insomnia, particularly among older caregivers (Eslami et al., 2018; Grant et al., 2003b; Streid et al., 2014b). Caregiving was identified as a burden on emotional health and a source of stress among informal caregivers (Eslami et al., 2018; Jagannathan et al., 2011; Olwit et al., 2015; Streid et al., 2014b). The informal caregiver's emotional responses to the physical state of the patient, their deteriorating health and fear of death were all integral to their experience (Aziato & Adejumo, 2014; Grant et al., 2003b; Makoae, 2009; Urizzi & Corrêa, 2007). Prolonged periods of caregiving produced mental health issues among informal caregivers, with some experiencing depressive symptoms such as tiredness, sadness, difficulty sleeping, lack of motivation and suicidal ideation (Olwit et al., 2015; Oyegbile & Brysiewicz, 2017b; Pesantes et al., 2017). Informal caregivers worried that they exacerbated the patient’s discomfort during caregiving, confirmed by a patient’s body language or complaint, which caused fear among informal caregivers (Makoae, 2009; Urizzi & Corrêa, 2007). Feelings of discomfort and repulsion were expressed by informal caregivers encountering bodily fluids. They feared the care recipients would misinterpret their behaviour as unwilling to help (Makoae, 2009). Feelings of stress often resulted from the uncertainty of the patient’s condition, their physical condition and unknown HIV status (Grant et al., 2003b; Makoae, 2009). Expressing their fear, one informal caregiver said:

> *It is true I was using those Dettols [disinfectants], but I am worried that I could be having it [HIV] already. Maybe he has infected me. I am worried that I have it because I did not protect myself when I was touching all that stuff and bathing him…no one gave me the gloves, not even the nurse at the hospital* (Grandmother) (Makoae, 2009 p.23).

The death and loss of a loved one were traumatic for some informal caregivers and contributed to their emotional burden (Jagannathan et al., 2011; Olwit et al., 2015; Oyegbile & Brysiewicz, 2017b).

2.8.2 Sacrificed lives and futures

Socially, participants described how caregiving had imposed restrictions on their lives and their autonomy and disconnected them from engaging in social activities (Oyegbile & Brysiewicz, 2017b). Stressors identified included a lack of independence and time to engage in social activities due to their presence in the hospital (Pesantes et al., 2017). Social isolation was described as feelings of loneliness, conflicting with other family members regarding decisions, lack of support from the broader family, being unable to fulfil other regular social activities outside the sick person (e.g. caregivers' children) and having to put their own social life on hold (Israëls et al., 2008a; Jagannathan et al., 2011; Pesantes et al., 2017; Streid et al., 2014b). The impact on the informal caregiver's inability to earn a livelihood was consistently experienced across the literature. Most participants reported having stopped working to care for their loved ones.

> *I abandoned my search for [a] job because I have to provide care. I felt that my future plan has been jeopardised since it is impossible for me to apply for a job from the hospital environment. My colleagues are employed and making future plans while I am here providing care* (Family caregiver 03) (Oyegbile et al., 2017, p.2627).

Informal caregivers faced difficulties in balancing their professional, family and caregiving roles, as they were unable to be physically present in all places (Bhattacharyya & Chopra Chatterjee, 2020b; Paget et al., 2016b; Streid et al., 2014b). Several mothers reported concerns about being unavailable to care for other children at home while others brought young infants to the hospital to remain with them (Mwangi et al., 2008b; Streid et al., 2014b). Some informal caregivers took on the caregiving of the children of the sick patient, extending their role beyond the hospital. One Ugandan caregiver providing care for her widowed HIV-positive sister reported that she cared for 20 children at home, including her sister's children (Streid et al., 2014b). Caregiving had impacts on marital relationships, with several articles reporting worry and fear about the well-being of spouses at home (Israëls et al., 2008b; Paget et al., 2016b; Streid et al., 2014b).

2.8.3 Bearing the cost of caregiving

There was evidence of informal caregivers bearing significant financial burdens due to caregiving (Bhattacharyya & Chopra Chatterjee, 2020b; Jagannathan et al., 2011). Being unable to work, many were wholly dependent on the financial support of other family members who sometimes failed to do so consistently. Caregivers assumed responsibility for the expenses associated with care, including the cost of drugs, transport to the hospital, food and other associated costs. Informal caregivers primarily relied on collective financial support from family networks to meet these costs (Eslami et al., 2018; Mwangi et al., 2008b; Pesantes et al., 2017; Streid et al., 2014b). In Nigeria, one informal caregiver noted:

> *I sleep outside on the veranda within the hospital with other family caregivers... I couldn't afford the hostel fee; if I pay the hostel fee, it may affect our ability to buy drugs, so I sleep outside* (Aziato & Adejumo, 2014, p.6).

2.9 Theme 3: Fulfilling familial obligations

This theme reflects the finding that for many informal caregivers, being in the hospital meant fulfilling an inevitable role, which was their duty. In some cases, this improved the ease of adaptation to the caregiving role and fostered closer relationships and empathy for their patients. In other cases, it brought an additional strain to the relationship.

2.9.1 Willingly fulfilling perceived duty

Most of the articles identified a common theme of familial obligation as the reason for undertaking a caregiving role (Grant et al., 2003b; Israëls et al., 2008a; Olwit et al., 2015; Oyegbile & Brysiewicz, 2017). There was evidence that healthy caregiver-patient relationships strengthened the informal caregiver's ability to fulfil their role (Olwit et al., 2015; Streid et al., 2014b). Participants reported that the time spent with the care recipient promoted a closer relationship between them and the patient, particularly when caregiving was prolonged (Oyegbile & Brysiewicz, 2017b). There was a sense of pride among informal caregivers at being able to perform a caregiving role for their family members, strengthening their relationships:

> *I feel fulfilled that I am able to provide care to my husband ... of 30 years... The type of care I provide for him makes him happy, and it has strengthened our love for each other* (Family caregiver) (Oyegbile et al., 2018, p.2629).

Caregivers empathised with their patients, notably when they observed that the patient was in pain. A feeling of empathy for patients in pain was linked to a sociocultural orientation that prepared caregivers for such emotional reactions to a '*suffering person*' (Aziato & Adejumo, 2014b; Olwit et al., 2015). Empathy was particularly pronounced in a maternal-child relationship where one informal caregiver noted, *'I'd rather die just to save him'* (KwaZulu Natal, age 71, mother caring for son) (Streid, 2014, p.321).

Where patients were resistant to receiving care, the literature identified a negative impact on the informal caregiver-patient relationship. Informal caregivers described some patients as 'difficult', 'demanding' and 'bad-tempered' and noted they refused medication or personal care. Informal caregivers experienced this as anger and frustration, and a source of stress (Makoae, 2009; Pesantes et al., 2017). While women primarily fulfilled the caregiving role, the duty of care also extended to male caregivers; however, this was not the norm. Caregiving roles performed by males were rationalised by the inconvenience of a woman leaving their household responsibilities, young children, or if they were not physically capable of doing caregiving work (Brown, 2012; Paget et al., 2016b; Zaman, 2004). A Bangladeshi study noted the inappropriateness of women to stay in a male hospital ward in breach of the practice of purdah (seclusion of females from males and strangers) as an explanation for informal male caregivers (Zaman, 2004a).

2.9.2 Adaptation to the role

In some cases, fulfilling this duty led to a sense of acceptance of the role and reduced the caregiving burden (Israëls et al., 2008a; Söderbäck & Christensson, 2007b; Streid et al., 2014b; Zaman, 2004). Informal caregivers were influenced by previous caregiving experience, which positively influenced their experience (Aziato & Adejumo, 2014b). The ability of informal caregivers to adapt to their role positively impacted their well-being (Paget et al., 2016b). Gaining skills as a caregiver led to feelings of confidence (Bhattacharyya & Chopra Chatterjee, 2020b; Park et al., 2020). Closely linked to confidence were feelings of resilience brought about by the acquisition of new skills, as described by one informal caregiver in India:

> *Baba (father) always took all major decisions, related to managing finances, property, major family decision. Now that he is not well, I am learning to manage those* (Bhattacharyya & Chatterjee, 2019, p., 88).

Coping strategies which supported adapting to the caregiving role included a positive attitude to the circumstances, achieved through good humour and avoiding seeing caretaking as an obligation (Aziato & Adejumo, 2014b; Olwit et al., 2015). One caregiver explained that sharing caregiving responsibilities helped her have a more autonomous life, reducing the emotional burden (Pesantes et al., 2017). Informal caregivers used religion, spirituality, prayer and meditation as sources of strength and resilience to manage anger and anxiety (Grant et al., 2003b; Olwit et al., 2015; Streid et al., 2014b). Family support networks were identified as an essential factor in coping where caregiving and its costs could be shared (Olwit et al., 2015; Oyegbile & Brysiewicz, 2017b; Pesantes et al., 2017). Informal caregivers came to rely on other informal caregivers as a source of support, developing a social bond over time at the hospital and taking responsibility for notifying each other in case of an emergency, ensuring that they got time for rest (Bhattacharyya & Chatterjee, 2019). According to one Bangladeshi informal caregiver:

> *We (family caregivers) stay here (in-patient ward) like a family. If one family caregiver has to go to call the nurse and leaves their patient alone, I stay*

> *near that patient and keep an eye on him or her* (45-year-old male caregiver) (Islam et al., 2014, p. 308).

2.10 Discussion of findings

The findings provide a rich, consistent account of the distinctive experience of informal caregivers in hospitals in low- and middle-income countries. Informal caregivers' experiences were mostly negatively reflected in their perceptions of their caregiver role and interactions with healthcare workers. Being an informal caregiver came at a major personal and financial cost to the caregiver. The findings highlighted that despite their negative experiences, informal caregivers felt a sense of responsibility to care for relatives, which enhanced their acceptance of the caregiving role.

The first theme, *the unwelcome but tolerated guest*, highlights that informal caregivers are an essential, albeit unrecognised group of care providers in hospitals in low- and middle-income countries. Underpinning this is the lack of power and control among the informal caregiver group in the hospital context, who have little influence over decision-making in patient care. Power relations within the hospitals were not fully explored in the reviewed literature; however, healthcare workers may have a sense of lack of power over aspects of patient care that are assumed by informal caregivers through cultural norms and economic imperatives (Hancart-Petitet et al., 2011; Wilson et al., 2012). Involving family members in patient care is associated with a range of positive outcomes, including reducing caregiver stress, increasing their confidence, improving patient empowerment and improving relationships with healthcare workers (Amakali & Small, 2013; Hassankhani et al., 2018a, 2019; Holmström & Röing, 2010; Stajduhar et al., 2010). Informal caregivers' physical presence was poorly accommodated, yet their necessity was underscored by cultural and contextual factors. Informal caregivers perceived healthcare workers as showing apathy towards their caregiving contributions, potentially deprioritising the need to educate informal caregivers based on their perceived low contribution. Unskilled provision of patient care is consistently associated with poorer patient outcomes (Global Health Workforce Alliance & WHO, 2013; Khosravan et al., 2014; Nakua et al., 2015). Addressing the chronic underfunding of healthcare workers is critical, but it is insufficient to address the patient care role provided by unskilled informal caregivers, given prevailing cultural norms.

Similarly, addressing infrastructural challenges in isolation is unlikely to be impactful; instead, a health system strengthening approach, recognising informal caregivers as unpaid health workforce members, is necessary (Global Health Workforce Alliance & WHO, 2013; Wilson et al., 2012). Changing perspectives about informal caregivers to recognise their contribution may open access to better resources, protection and education for their inclusion as care team members (Horng et al., 2016; Landers et al., 2012; Wilson et al., 2012). Legislation encompassing how nurses should supervise unqualified service providers has been suggested in Cambodia and could be considered elsewhere (Sakurai-Doi et al., 2014). Continued future reliance on the informal caregiver group to provide patient care cannot be assured in modern contexts where urban migration for employment and women working outside the home may reduce the availability of informal caregivers in the future (Allegri et al., 2007; Graves et al., 2010; Park et al., 2020).

The second theme, *enduring personal sacrifice*, emphasises the burden of caregiving, which has mainly been experienced as a stressor prevalent in the literature (Britten et al., 2002; Hassankhani et al., 2018a; Holmström & Röing, 2010; Pesantes et al., 2017). This is consistent with the theoretical framework of the Stress Process Model, which identifies caregiver stress as a complex response to internal and external demands affecting psychological, relational and social resource interactions (Pearlin et al., 1990). The burden of caregiving extends to marital and familial relationships and places strain on these (Kipp et al., 2007; Streid et al., 2014b). However, fulfilling a caregiving role also leads to satisfaction and the development of closer relationships with the patient (Grant et al., 2003; Israëls et al., 2008; Oyegbile & Brysiewicz, 2017; Streid et al., 2014). Informal caregivers are frequently women, potentially contributing to enduring gender inequality through perpetuating a systemic burden of denial of paid employment and sustained poverty (Okereke et al., 2020; Rückholdt et al., 2019). The need to develop and integrate psychosocial interventions such as peer support, stigma and anxiety reduction programmes is evident to support caregivers to continue their role (Acri et al., 2017; Coleman et al., 2015; Tawiah et al., 2015).

The direct and indirect financial costs associated with caregiving are well discussed in the literature but may have a more pronounced impact in low- and middle-income countries (Burroway & Hargrove, 2018; Graves et al., 2010; Park et al., 2020). Financial concessions for informal caregivers, including an accommodation allowance and costs of meals and transport, could be considered (Hassankhani et al., 2018b; Stajduhar et al., 2010).

The third theme, *fulfilling familial obligations,* reflects the sense of duty among caregivers and their resilience in adapting to their role. They seek out family support, forge alliances with other caregivers and use spiritual practices to cope with the informal caregiver role (Grant et al., 2003b; Streid et al., 2014b). To maintain a good quality relationship between the caregiver and patient, supportive programmes have effectively reduced caregiver distress and fostered high self-esteem, which has a protective effect on the relationship (Bouchard et al., 2019; Mroz et al., 2018). The gendered dimension of caregiving is well addressed in the literature, and women suffer a more significant burden from caregiving. Gendered relations of caregiving need to be addressed in policies and practices to reduce the impact on women (Lapsley et al., 2020; Swinkels et al., 2019).

The resilience of caregivers is associated with positive impacts on their quality of life and ease of transition to the role (Palacio et al., 2020). Developing culturally appropriate interventions that foster coping strategies among informal caregivers is necessary to support their adaptation to the role (Hadley et al., 2007b; Palacio et al., 2020; Swinkels et al., 2019).

A gap identified in the literature throughout the review is the lack of exploration of informal caregivers' potential exposure to disease. The patient care practices they perform, their exposure to the hospital environment, their lack of access to infection prevention and control infrastructure, and a limited understanding of disease transmission and preventative practices may present an increased risk. The occupational risk of disease transmission among healthcare workers is well established, and a similar risk may exist among informal caregivers who perform patient care tasks (Lazzari et al., 2004; Pittet, 2014). No study in this review identified if an informal caregiver was exposed to or transmitted an infectious agent in the hospital. However, this would not be unexpected, as low- and middle-income countries frequently lack the necessary laboratory support and hospital-acquired infection surveillance systems necessary for hospital-acquired infection reporting (Nejad et al., 2011; Zingg et al., 2015). Several articles elsewhere have acknowledged the role of family members as contributors to hospital transmission of disease (Allegranzi et al., 2013a; Nejad et al., 2011; Park et al., 2020; Pittet, 2014; Shahida et al., 2016; World Health Organization., 2011; Zingg et al., 2015). In today's context of the COVID-19 pandemic and emerging pathogens, adherence to best infection prevention and control principles by all people in hospitals is essential; this cannot exclude informal caregivers who function within the hospital system. In addition, this review did not explore the perception of healthcare workers towards informal caregivers, which is an area for further research that may inform educational and supportive interventions needed to improve the relationship with informal caregivers and address their inclusion within the hospital system.

2.11 Strengths and limitations

The included articles had a broad geographical range, but many countries where informal caregivers are typical were underrepresented. An observation among the final included articles was that a majority used in-depth interviews or focus groups as their data collection method. Only five articles adopted observation as a component of their data collection. There can be disparities between self-reported and observed behaviours, indicating the need for additional observational qualitative research in this field (Dixon-Woods et al., 2005). This indicates a need for additional qualitative observational research to understand the experience of informal caregivers further.

2.12 Conclusions

This meta-synthesis highlights that informal caregivers perform an essential caregiving role but occupy a peripheral and voluntary space in hospitals. In a context where a critical shortage of healthcare workers and a cultural reliance on informal caregivers persists, continuing to exclude them from provision within the health system may be detrimental to patient outcomes and impact the broader population's health and health system. The burden of caregiving is significant, and the hospital is ill-equipped to support informal caregivers while being critically reliant on this informal, poorly-served workforce. The need to support informal caregivers to perform their role safely has been underscored, and efforts to incorporate their perspective into existing hospital cultures are necessary. This further identifies the rationale to better understand the informal caregivers' role in infection prevention and control as a specific risk associated with providing patient care, which provides the foundation for the research detailed in the next chapter.

3 Methodology

In this chapter, I outline the methodological approaches used in the study, including a revisit of the research aim and objectives. I discuss the research paradigm rationale for methodological choices, emphasising systems thinking. I justify the selection of qualitative methodology, focusing on a detailed discussion of the chosen focused ethnography methods, and reflect my position as the researcher within the study.

3.1 Aims and objectives and research question

3.1.1 Aim

The aim of this study is to explore the role of informal caregivers in infection prevention and control in hospitals in low-middle-income countries.

3.1.2 Objectives

1. To determine what patient care practices informal caregivers perform in the hospital and the associated risk of infection control of these practices.
2. To determine any infection control practices informal caregivers engage in during the course of their caregiving practices.
3. To explore informal caregivers’ perceptions of their role in infection control during the course of their caregiving practices.
4. To explore healthcare worker's perception of the role of the informal caregiver in infection prevention and control in the hospital.

3.1.3 Research question

How do informal caregivers experience their role in infection prevention and control in hospitals in Vietnam?

3.2 The constructivist paradigm

> *There are many radically different, yet "equally valid" ways of knowing the world, with science being just one of them* (Boghossian, 2006, p.2).

In embarking on this research journey, I chose to anchor my exploration within the constructivist paradigm, thereby establishing both the ontological and epistemological underpinnings of my study. Rubin and Rubin (2005a) explain a paradigm as the overarching philosophical or ideological stance, a system of beliefs about the nature of the world that, when applied in the research setting, will form the assumptive base from which we go about producing knowledge. A research paradigm consists of ontology, epistemology, methodology and methods (Crotty, 1998). As a constructionist researcher, I understand knowledge as a socially constructed entity, with reality as subjective and intricately shaped by cultural interactions and environmental contexts (Goldman, 1979; Guba & Lincoln, 1989; Lauckner et al., 2015; Mertens, 2009). Within the constructivist framework, I recognise the coexistence of diverse and equally valid views of the world, leading me to interpret the meaning participants attribute to their experiences of informal caregiving in a Vietnamese hospital (Lincoln, 1998; Mauthner & Doucet, 2003; Rubin & Rubin, 2005a).

Navigating through the constructivist lens, I have emphasised exploring the dynamics among individuals within specific contexts where interactions occur (Creswell, 2003). This approach, fostering a subjectivist transactional perspective of knowledge production, aligns seamlessly with my research aim: to comprehend the nuanced complexities of the informal caregiver's role in infection control within the Vietnamese hospital context while considering their interactions with health workers and the hospital environment (Guba & Lincoln, 1990).

The constructivist approach encourages an inductive process to research rather than starting with a research question which addresses a pre-defined hypothesis. My research adopts an exploratory approach to broadly explore the role of the informal caregiver in infection prevention and control rather than seeking to answer more narrow-focused questions on this topic, which is well aligned with the constructivist approach.

Given the distinctive context of a hospital subculture in Vietnam, where unique cultural norms prevail, examining cultural contexts becomes particularly pertinent in the realm of constructivism. As a paradigm, constructivism delves into understanding how culture intricately moulds the subjective meaning of experiences (Creswell, 2003). This exploration aligns with the ethnographic paradigm, offering a lens to unravel the complex interplay between cultural dynamics and the subjective interpretation of lived experiences within the hospital setting.

From an epistemological perspective, I adopted a subjective and transactional approach to producing knowledge (Geanellos, 2000). The findings in my study were created through interactions between me as the researcher and the participants (Guba & Lincoln, 1989). Engaging in interviews, observations and occasional social interactions, I aimed to gain a profound understanding and interpret the role of informal caregivers in infection control.

3.3 Rationale for a methodological approach

I chose a qualitative approach for my research, aligning with a constructivist paradigm to address the research aims. The overarching aim of qualitative research is to comprehend, describe and interpret social phenomena from the perspectives of individuals, groups and cultures (Holloway & Wheeler, 2013; Pathak et al., 2013). Key characteristics of qualitative research include the emergence of data free from predetermined theoretical frameworks, contextual understanding within naturalistic settings, the production of thick descriptions for data interpretation and a reflective examination of the researcher's role as a tool throughout the process (Holloway & Wheeler, 2013; Mauthner & Doucet, 2003; Pathak et al., 2013).

Prior to deciding to adopt a qualitative approach, I considered a mixed methods approach and weighed its advantages in offering a comprehensive investigation by combining quantitative and qualitative methods. Mixed methods research can facilitate a more thorough investigation of data, and the triangulation of various methods can strengthen findings (Regnault et al., 2018). It also aims to transcend paradigm wars through critical realism, acknowledging methodological eclecticism; however, the theoretical debate on mixing qualitative and quantitative research persists (Regnault et al., 2018). Ultimately, the criticisms regarding the reliability of mixed methods, including inconsistent results and a lack of clear guidelines, informed my decision (Creswell, 2003; Clark et al., 2008). Coupled with the complexities involved, demanding significant methodological skills and additional resources led me to reject this approach (Creswell, 2003). Given the exploratory nature of my research, focusing on an in-depth investigation into the role of informal caregivers, I concluded that a qualitative approach, underpinned by a constructivist paradigm, was most suited to provide rich, in-depth data on the experiences of this group.

3.4 Choosing a qualitative methodology

The selection of a specific qualitative method for addressing the research question was informed by the nature of the inquiry and the depth of understanding sought. I considered a range of approaches to address the research question, including phenomenology, grounded theory and ethnography. Some commonalities exist across all these qualitative approaches, including conducting research in a naturalistic environment, sampling approaches, data collection methods, eliciting rich data and representing the participant's experience. However, ethnographic research was most closely aligned with the intention of this research for its focus on cultural context and social dynamics aiming to describe patterns of shared behaviour in a culture, focused on ‘culture’ in the sense of shared beliefs, practices and feelings (Lewis, 2015).

Phenomenology would have been an appropriate method to focus on describing the subjective experiences of informal caregivers. Phenomenology is concerned with understanding the lived experience of a phenomenon (Heinonen, 2015). Engaging with narrative accounts and interpreting texts to derive meaning is a key feature of this methodology (Crotty, 1998; Tan et al., 2009; Koch, 1995; Ritchie et al., 2013). While the characteristics of phenomenology align with my research, the reliance on translation for interviews in Vietnamese may limit the depth of interpretation of narrative texts. Furthermore, the flexible and emergent nature of phenomenology, without a prescribed order, contrasts with the well-explored aspects of infection control in my research, where I have specific questions to address (Ajjawi & Higgs, 2015; Barnett et al., 2017).

I considered grounded theory but eliminated it due to its focus on generating conceptual theories, which diverged from the specific aims of my study. The intended outcome of grounded theory is to generate a conceptual theory that accounts for a pattern of behaviour or elaborates on previously existing theories (Charmaz, 2006; Glaser & Strauss, 1967; Lewis, 2015; Smith, 2001). Grounded theory, rooted in symbolic interactionism, explores the subjective meanings individuals attribute to social interactions, encompassing cultural and individual variations (Glaser, 1967; Tie et al., 2019). While grounded theory involves the emergence of theory from data, its emphasis on theory construction did not align with my research objectives (Birks, 2015; Charmaz, 2006; Tie et al., 2019).

3.5 Ethnography

Rooted in a constructivist epistemology, an ethnographic approach is well suited to address the cultural perspectives of people within a specific context, and the findings can have a useful application in a hospital setting (Higgenbottom et al., 2013). Ethnography originated in social anthropology and evolved as a way to understand people's social and behavioural norms within specific cultures (Atkinson & Hammersley, 1994). In ethnography, the study of culture relates to people's behaviours, daily practices, activities and perspectives (Atkinson & Hammersley, 1994; Fetterman, 2010). Ethnography requires that these practices, behaviours and activities be understood in the context and their influences on them, such as rituals, structure, environment and symbols for wholism (Fetterman, 2010). This aligned well with my research exploring the behaviours and experiences of informal caregivers in infection control as a group and within the hospital setting in Vietnam.

Aligned with a constructivist epistemology, ethnographers’ ontological perspectives support the belief of multiple, equally valid world views (Boghossian, 2006; Atkinson & Hammersley, 1994). Ethnographers conduct research by interacting with people in their culture and everyday lives, assessing multiple perspectives of the reality of both the participant and the researcher's perspective of these behaviours where they occur (Atkinson & Hammersley, 1994). Interpreting what is observed, I strived to produce a rich narrative to reflect the complexity of these multiple perspectives. There are two distinct perspectives of the *etic* and *emic,* terms derived from the field of hermeneutic linguistics, referring to traditional research strategies used to study phenomena in different cultures (Boyle et al., 2015; Gobo, 2008; Greene, 2000). The *etic* view of culture is the perspective of the outsider, in this case, me as the researcher who adopts a cultural lens to understand behaviours witnessed in the participant environments (Fetterman, 2010). In this study, the emic view is that of the insider community of informal caregivers, focusing on the intrinsic cultural dimensions that are meaningful within their particular society (Boyle et al., 2015; Greene, 2000). Ethnography allows for the exploration of informal caregivers' usual activities and interaction patterns within a Vietnam hospital. Field observations provide an *etic* point of view of the role of the informal caregiver in hospitals, while interviews and researcher interactions with participants provide *emic* meaning to the practices observed by researchers (Atkinson & Hammersley, 1994; Fetterman, 2010). I combined both perspectives to provide a true but conditional account of what I observed.

3.5.1 Focused ethnography

This study is a focused ethnography, a variation of traditional ethnography (Higgenbottom et al., 2013). It emerged within the healthcare field as a pragmatic solution in contexts where traditional ethnographies were not feasible (Cruz & Higginbottom, 2013). Focused ethnography responded to a need for researchers to conduct smaller-scale projects in everyday settings when there is a clearly defined problem to investigate (Cruz & Higginbottom, 2013). This focused lens on the defined problem means projects can be shorter in duration and can include multiple sites through intensive data collection (Higgenbottom et al., 2013).

Focused ethnography shares many characteristics with traditional ethnography and other qualitative methodologies, including the generation of knowledge along an inductive paradigm through an iterative, reflective, cyclical research process and producing rich contextual data to gain an in-depth holistic understanding from the perspective of the participants (Atkinson & Hammersley, 1994; Fetterman, 1998; Parker, 2007; Roper & Shapira, 2000). However, whereas ethnography traditionally relies on the emergence of sensitising concepts through observation during long periods of immersion within a culture, focused ethnography involves the selection of pre-specified research questions informed by the researcher's background, the use of intermittent purposeful field visits, multiple data collection methods and an emphasis on the data analysis of the research process (Atkinson & Hammersley, 1994; Borbasi et al., 2005a; Dixon-Woods et al., 2012). This approach fits within this study's pre-defined scope of interest, which is informed by my background as an infection control advisor in low-income countries and my clinical background as a nurse. In this study, the culture of informal caregivers in hospitals in Vietnam was examined by understanding the perspectives, behaviours and context related to it.

Table 3.1: Comparison between conventional and focused ethnographies

Conventional Ethnography	Focused Ethnography
Long-term field visits	Short-term field visits
Experientially intensive	Data analysis intensity
Time-intensity	Time-intensity
Writing	Recording
Solitary data collection and analysis	Data session groups
Open	Focused
Social fields	Communicative activities
Participant role	Field-observer role
Insider knowledge	Background knowledge
Subjective understanding	Conservation
Notes	Notes and transcripts
Coding	Coding and sequential analysis

Source: Replication of a table from (Cruz and Higginbottom, 2013)

3.6 Underlying systems thinking

Although distinct, systems thinking and ethnography can mutually enrich studying complex social phenomena. Ethnography concerns cultural contexts, offering insights into human behaviour, beliefs and societal structures. In contrast, systems thinking emphasises a system's interconnectedness, considering feedback loops, emergent properties and complexity. Integrating these approaches captures the richness of cultural practices while understanding broader systemic influences.

Applied to this research, systems thinking is a lens through which to view complex problems such as infection control and hospital systems. It is widely used in the clinical application of infection control. Systems thinking is a philosophical and methodological perspective drawing from systems theory (Xia et al., 2017). A system is a cohesive entity characterised by interconnected and interdependent parts collaborating to fulfil a shared purpose, where changes in one part impact both that specific component and the entire system at multiple levels (Hassan et al., 2020). The concept of 'holism' centres on understanding the relationships and interactions between system components, aiming to develop a comprehensive understanding that explains human behaviour influenced by the interplay of multiple interconnected systems (Meyer & O’Brien-Pallas, 2010).

Applied to infection control, systems thinking serves as a lens to view complex problems in healthcare. It has been widely used in clinical applications and offers a comprehensive perspective on infectious disease transmission (Hassan et al., 2020).Systems thinking has been applied to the recent COVID-19 pandemic to offer a novel and comprehensive perspective examining the process of infectious disease transmission as a system in relation to its interaction with human behaviours, the environment and society (Hassan et al., 2020; Xia et al., 2017).

Systems thinking aligns with the constructivist paradigm, both emphasising a non-reductionist approach and recognising the subjective lens through which individuals perceive the world (Lincoln, 1998). In healthcare, adverse events from poor infection control practices are seen as unintended consequences through the interaction of the various components of the healthcare system (Hassan et al., 2020; Storr et al., 2016; Fitzpatrick et al., 2008; Loke et al., 2007).

This research adopts a systems thinking lens to investigate the role of informal caregivers in infection control. It provides a framework to understand the informal caregiver role within the broader health system, emphasising the potential for strengthening one part to induce change in the overall system (Kirk et al., 2007). It further provides a lens through which to view informal caregivers' interactions within the healthcare system, their tasks and the associated infection control risks and recognises the need for behaviour modification at the complex system level. The systems thinking lens informs the perspective of my research that strengthening one part of the system can lead to a change in the overall system (Germain, 1978; Meyer & O'Brien-Pallas, 2010).

3.7 Researcher as a data collection instrument

In my focused ethnography on informal caregivers in a Vietnamese hospital, I assume a pivotal role as the primary data collection instrument, aligned with the theoretical framework articulated by Hammersley and Atkinson (1995). The concept of 'researcher-as-instrument' highlights my active involvement in the research process, immersed in the natural settings of the research. In practice, I engaged in multiple data collection methods, including prolonged, systematic observations, interviews and interactions with participants, all tailored to the specific context of the hospital. I aimed to develop a rapport with the research participants and create a conversational space for informal caregivers to share their experiences and life worlds (Turato, 2005, Owens, 2006). This participatory approach facilitated the capturing of the richness of social practices, interactions and meanings within the unique context of informal caregiving in a hospital setting.

In my study with informal caregivers in a Vietnamese hospital, I navigated between the insiders' emic perspective and the outsiders' etic viewpoint. Embracing the emic viewpoint, I immersed myself in the participants' insider understanding, valuing the internal meanings and interpretations of the caregivers within the hospital setting. Simultaneously, I adopted an etic perspective, stepping back to analyse the situation from an outsider's viewpoint, informed by existing theories. This dual approach was crucial as it allowed me to capture the authentic experiences and cultural nuances of informal caregivers while providing an analytical distance to understand the healthcare system's dynamics comprehensively (Atkinson & Hammersley, 1994). This approach ensures a nuanced exploration of the caregivers' role in infection control practices.

3.8 Selecting data collection approaches

I utilised ethnographic observations and interviews as the primary data collection methods. The rationale for these choices is discussed below.

3.8.1 Individual interviews vs focus groups

Focused ethnographies have employed both individual interviews and focus groups or a combination of the two for data collection (Cooper & Endacott, 2007). Focus groups involve open-ended discussions among individuals sharing relevant characteristics and can stimulate conversation and offer reflection opportunities as an advantage over solo interviews (Rubin & Rubin, 2005b). However, due to hierarchical cultural dynamics in Vietnam, where a reluctance to be vocal and deference is highly valued, focus groups were deemed less appropriate for this study's informal caregiver participant group (C. V. Nguyen & Nguyen, 2019). Lacking insider cultural knowledge, I faced challenges in understanding participants' social stature, the underlying social dynamics and how these factors influenced their willingness to engage in open discussions. Language interpretation challenges and practical considerations, such as disrupting caregiver duties, led to the choice of individual interviews over focus groups as a more suitable data collection method (Rubin & Rubin, 2005b).

3.8.2 Structured interviews vs unstructured interviews

Given that the pre-specified research questions aligned with a focused ethnographic approach, I opted for a semi-structured approach, which was more appropriate for this study. In the focused ethnographic literature, a majority of previous articles used a semi-structured interview approach based on a flexible interview schedule. Typically, the interview schedule is derived from previous literature, initial scoping and pilot articles and is informed by the researcher's background (Higgenbottom et al., 2013; Rubin & Rubin, 2005b). Interview schedules tend to be iterative and may undergo refinement during the data collection period as new concepts and topics to explore emerge (Carroll et al., 2016). Unstructured interviews have also been used in focused ethnography to a lesser extent. This approach to interviewing can generate large amounts of data that may be unrelated to the research question (Rubin & Rubin, 2005b).

3.8.3 Ethnographic observations

In this study, I chose observation as one of the key data collection methods to facilitate an in-depth exploration of the informal caregivers in hospitals in Vietnam. Observation as a research method '*combines participation in the lives of the people being studied with the maintenance of a professional distance that allows adequate observation and recording of data'* (Fetterman, 1998). Observation is especially well suited to research questions for which there is little pre-existing information, which requires study in a natural context to explore people's behaviour in ways they may not be able to self-report (Borbasi et al., 2005b; Dixon-Woods et al., 2012; Higginbottom, 2011). Observations are often used in conjunction with an interview to triangulate and confirm themes within the data (Atkinson & Hammersley, 1994).
In Chapter 2, the systematic review identifies a lack of observational data on informal caregivers in hospitals in low- and middle-income countries. Most articles have relied on interviews and focus groups, but interviews alone may offer an incomplete understanding of the role of informal caregivers in infection prevention and control. Observational data reveal attitudes and beliefs not necessarily reported by interviewees, highlighting a disparity between reported and observed behaviour (Borbasi et al., 2005b; Fetterman, 1998). Observations also provide an opportunity for informal interviews and 'on the spot' clarifications of observations, adding further depth and context to the data (Borbasi et al., 2005b; Higgenbottom et al., 2013).

3.8.4 Participant vs non-participant observations

Observations can be participant or non-participant (Spradley, 1979). There is no defined best method for conducting observations, and the consensus in the literature is that the best method is often developed personally through researcher experience (Atkinson & Hammersley, 1994; Fetterman, 1998; Higgenbottom et al., 2013).

Participant observation is characterised by the researcher interacting with participants in everyday life in a naturalistic setting while collecting data (Cruz & Higginbottom, 2013; Atkinson & Hammersley, 1994; Spradley, 1979). Non-participant observation is characterised by the researcher being separate from the activities observed without actively participating in the environment (Atkinson & Hammersley, 1994; Spradley, 1979).

Focused ethnography typically uses the observer-as-participant role, which is less time-intensive than that of the participant-as-observer preferred by more traditional methods (Angrosino, 2008; Atkinson & Hammersley, 1994; Fetterman, 1998; Parker, 2007; Roper & Shapira, 2000). The observer-as-participant role facilitates the researcher to collect specific information without being an active participant in the participants setting, supporting the maintenance of objectivity in ethnographic research where rapport and relationships are developed between researcher and participant but without the same degree of risk of losing objectivity common in the participant-as-observer roles (Atkinson & Hammersley, 1994; Bracco et al., 2014; Higgenbottom et al., 2013). In this study, I adopted the observer-as-participant role aligned with my methodological approach and maintained a reflexive account of this role.

3.9 Conclusion

In this chapter, I offered a comprehensive overview of the methodology employed in this study, providing the rationale behind the chosen approaches. The forthcoming chapter will discuss the research methods, thoroughly examining how the study was conducted.

4 Methods

4.1 Introduction

This chapter discusses the research methods and the rationale for their use in this focused ethnography. A description of the details of the research conducted is provided. Ethical issues are addressed, and a discussion on the process is outlined. Reflexive accounts are interwoven throughout the chapter to increase transparency in the research design and conduct.

4.2 Setting

For this study, I collected data in adult inpatient departments in the neurosurgical unit, general medical unit, emergency unit and orthopaedic unit at a secondary-level acute public hospital in Hanoi, Vietnam, during four intermittent weeks from August to December 2018. The hospital had a capacity for approximately 600 inpatients and provided services through an emergency room, surgical, medical, intensive care and outpatient departments.

4.3 Entering the field

When conducting this research, I was employed in an international global health organisation stationed in Hanoi, Vietnam. I was deeply involved in supporting the infection control department at the Ministry of Health and regularly engaged with hospitals across the country. My professional engagement allowed immersion in Vietnamese hospital culture, aligning well with the focused ethnographic approach, which benefits from shorter immersion periods based on the researcher's background (Cruz & Higginbottom, 2013). The hospital in Hanoi where this research was conducted was not a hospital where I was present for any professional duties. Before data collection, I visited the research hospital site multiple times throughout the ethical approval process. These visits involved meetings with hospital administration, touring the facility and discussing with nurses overseeing clinical units. This collaborative effort established rapport and informed the hospital-approved research schedule.

Navigating access to the hospital required careful consideration of the daily routine. I initially intended to conduct observations across the spectrum of the day; however, this was unfeasible under guidance from the hospital administration. I strategically planned observations and interviews based on the hospital's schedule, avoiding disruption during nursing shifts, clinical rounds and lunch breaks. Despite facing external limitations imposed by the hospital administration, such as restricted access to specific units and the exclusion of night-time observations, I adhered to their decisions. The lack of autonomy over access was documented in my reflection diary, highlighting the challenges encountered during the research process.

4.4 Population

This study included informal caregivers and healthcare workers in the hospital. Eligibility for participation of informal caregivers is shown in **Table 4.1**, and eligibility for participation of healthcare workers is shown in **Table 4.2**. These criteria ensured that informal caregiver participants were those in the hospital for more than 48 hours, aligning with the definition of hospital-acquired infections (Bagheri Nejad et al., 2011; WHO, 2002). Inclusion extended to infection control staff; none were identified during the research at the hospital site.

Table 4.1: Informal caregiver participant inclusion and exclusion criteria

Informal Caregivers	
Inclusion criteria	**Exclusion criteria**
• Meet the definition of an informal caregiver. • Informal caregivers of patients admitted longer than 48 hours in inpatient wards of hospital observation sites.	• Informal caregivers of patients in non-inpatient settings such as outpatients, clinics and emergency rooms. • Informal caregivers under 18 years old for protection reasons.

Table 4.2: Healthcare worker participant inclusion and exclusion criteria

Healthcare Workers	
Inclusion criteria	**Exclusion criteria**
• Healthcare workers employed in the hospital unit being used as an observation site for more than one year. • Healthcare workers employed as infection control staff in the hospital.	• Healthcare workers with less than one year of experience at the hospital site

4.5 Sample

In focused ethnography, as with most qualitative research, there is no predefined ideal sample size, and it varies according to the research aims (Glaser & Strauss, 1967; Higgenbottom et al., 2013). Data saturation most often dictates the sample size in focused ethnography (Higgenbottom et al., 2013; Malterud et al., 2016; Vasileiou et al., 2018). Data saturation, distinct from grounded theory's theoretical saturation, focuses on saturation at the data collection level rather than at analysis (Saunders et al., 2018). This view of saturation focuses on how much data is needed until nothing new emerges, achieving informational redundancy (Sandelowski, 2008; Saunders et al., 2018).

My research used both interviews and observations as data collection methods. The proposed sample size for interviews was initially estimated to be between 8-10 informal caregivers and 6-8 healthcare workers. During the research, it became apparent that healthcare workers had valuable insights to offer in their perspectives of informal caregivers, so more interviews were conducted with them than initially anticipated. Final sample sizes were determined by the participants' willingness to engage and share experiences to the point of data saturation. Data saturation was determined to be reached when the same comments were heard repeatedly during interviews (Saunders et al., 2018). When all relevant topics were investigated, and no new interpretations were generated from additional participation, data collection ceased and analysis began (Borbasi et al., 2005a; Dixon-Woods et al., 2012; Fetterman, 1998; Higginbottom, 2011; Sargeant, 2012; Saunders et al., 2018).

4.5.1 Purposive sampling

To capture a sample of information-rich, potential informal caregivers and healthcare worker participants to explore the research question, a purposive sampling approach was employed, using snowballing (Guetterman, 2015a; Suri, 2011). Purposive sampling gathers information-rich cases from participants with a range of experiences to understand their varying perspectives (Patton, 2001a). These participants intentionally have the most knowledge and experience of the topic under investigation and are willing to participate and articulate their experience (Newington & Metcalfe, 2014; Patton, 2001b; Spradley, 1979). However, there is a lack of clear guidance on conducting purposive sampling and challenges in achieving data saturation where the range of variation among information-rich participants is unknown (Palinkas et al., 2015a).

Snowballing, a participant referral method, is valuable in cross-cultural settings, leveraging participants as 'culture brokers' to enhance research engagement (Guetterman, 2015b; Sargeant, 2012; Essén et al., 2011). Snowballing has been criticised for its implementation's lack of substantive definition and instruction (Kirchherr & Charles, 2018). Participants can share similar characteristics through connection, a criticism where sample diversity is necessary for valid research findings (Allen, 2017; Kirchherr & Charles, 2018). However, for this study, the sample was a group of informal caregivers within a hospital rather than a community, so connections to each other were not based on social characteristics or relationships.

In this study, after recruiting initial participants from the informal caregiver and healthcare worker groups, a snowballing approach was employed. For informal caregiver participants, the intention was to achieve maximum variability in domains such as caregiving experience and type of illness (Higginbottom et al., 2015). However, it was influenced by access within the hospital. Healthcare worker recruitment was initiated by hospital administrators' gatekeepers, allowing flexibility for sampling and resampling to ensure theoretical saturation (Miles & Huberman, 1994).

4.6 Recruitment

The healthcare worker recruitment involved a hospital administration member facilitating introductions in clinical units, negotiated in advance for trust-building and endorsed by hospital management. This approach aligns with the observed importance of local champions as 'gatekeepers' for participant engagement (Guetterman, 2015a; Alaei et al., 2013). It aimed to establish rapport, utilise local champions in each unit and navigate hierarchical structures within Vietnamese hospitals, where the administration oversees all research conducted. For informal caregiver recruitment, healthcare workers facilitated introductions due to their proximity to patients and informal caregivers, practicalities and language barriers. A qualified medical translator was engaged for verbal and written translations throughout the study.

The study was advertised within the hospital two weeks before data collection using Vietnamese posters in visible locations in the medical and surgical units, which were observation sites (see Appendix 8). Informal caregivers had multiple options to express interest, such as through a locked box at the nurse’s station, via a health worker, or by texting a dedicated phone number. A participant sheet in Vietnamese was hand-delivered to those interested (see Appendix 9). Healthcare worker participants could also register their interest in the locked collection box or inform the hospital administrator or researcher through a dedicated phone line. A specific booklet in Vietnamese was made available to all healthcare workers involved in interviews or working in the hospital units (see Appendix 10). All participants were given at least 24 hours to decide, emphasising voluntary participation and the option to withdraw verbally during or up to six months after data collection through my contacts or the hospital administrator.

4.7 Data collection overview

Data collection occurred in adult inpatient departments in the neurosurgical, general medical, emergency and orthopaedic units. All interviews were conducted in Vietnamese with a qualified medical translator, recorded, transcribed and translated into English. Field notes were maintained throughout the data collection period to record observed behaviour and activities I witnessed. A reflective diary to provide contextual information was also maintained throughout the data collection period.

4.7.1 Data collection methods

The following methods of data collection were employed for this study:

1. Observation of informal caregivers recorded in field notes
2. Semi-structured interviews with informal caregivers and healthcare workers to explore phenomena of interest and clarify findings from observations
3. Reflection diary: to explicitly recognise my role as a researcher, identify biases and for use as a quality mechanism

4.7.2 Participant observation

Participant observation encompasses broader descriptive observation and, in focused ethnography, more targeted observations, benefitting from the researcher's expertise and well-defined research questions (Higgenbottom et al., 2013; Spradley, 1980). Overt observation, where participants are fully aware of the researcher's intent, is preferred over covert observation due to ethical concerns (Delamont, 2004; Hammersley, 2006a; Rubin & Rubin, 2005b). In this study, I chose overt observation to examine informal caregivers' interactions with patients in the hospital, providing advantages of enhanced access, ethical transparency and open field notetaking. The limitations of this approach included the observer effect, where the researcher's presence influences the behaviour of those being studied (Atkinson & Hammersley, 1994; Spradley, 1980). While I made efforts to be unobtrusive, blending in was challenging, leading to reflections I provide later in the chapter. Sometimes, I refrained from writing notes and recorded them later to avoid breaking the naturalistic setting.

Field notes were used to record observed behaviour and activities witnessed by me were captured in text in a field notes diary and were a key source of raw data for analysis (Fetterman, 1998). Spradley (1979) offers a framework to capture field notes with nine observational dimensions of space, actors, activities, objects, acts, events, time, goals and feelings, which informed the process for collecting field notes in this research (Spradley, 1979). I focused on observing informal caregivers' patient care activities, related infection control practices and any omissions in practice using an observation guide I developed based on the World Health Organization's core components of infection prevention and control. I later refined it for flexibility to capture the broader context of interactions with people, healthcare workers and the environment.

A number of natural conversations arose with informal caregivers during these observation periods where clarification on actions was sought or where conversation arose. Information from these conversations was recorded immediately after leaving the research site in field notes, providing context for the analysis of the observational data.

4.7.3 Semi-structured interviews

Semi-structured interviews supported observations and provided direction for future observations to collect data on what was not observed and, on the feelings, and perceptions of the caregivers (Fetterman, 1998; Higgenbottom et al., 2013). I conducted interviews with healthcare workers exploring their perception of the role of informal caregivers, organisation of clinical care, infection control practices and their experience in interaction with informal caregivers (see Appendix 11 for a flexible topic guide for healthcare workers). I conducted interviews with informal caregivers, exploring their experiences, roles, understanding of infection control practices and interactions with healthcare workers (see Appendix 12 for the flexible topic guide for informal caregivers). The interview guides were developed as per the research aims, and the open-ended semi-structured interview was influenced by relevant literature. This guide was used to provide focus to the interviews and was refined as per data emerging from other interviews and observations.

Healthcare worker interviews were conducted in a private staff room in the hospital. Informal caregiver interviews occurred in a naturalistic environment at the bedside amid the wards' daily activities. Conducting individual qualitative interviews at a patient's bedside in a busy hospital setting, although convenient, may compromise participant comfort and openness; however, the risk of removing them from their duties as well as finding a private space informed against it (Rubin & Rubin, 2005b; Senthilkumaran et al., 2015; Eggenberger & Nelms, 2007).

Notes were taken throughout the interviews, and more comprehensive interview notes were written up the same day after leaving the research site. All interviews were conducted in Vietnamese with a qualified medical translator, recorded, transcribed verbatim in Vietnamese and translated into English by the same translator.

4.7.4 Reflection diary

Maintaining a reflexive diary alongside field notes is crucial for contextualising observations (Higgenbottom et al., 2013). A reflexive diary aids in interpreting observed phenomena, defining the researcher's role and identifying biases (Fetterman, 1998; Higgenbottom et al., 2013). Reflexive diaries contribute to data quality and rigour, serving as a gatekeeper to provide additional context on interpretations drawn to ensure the results present a true reflection of the caregivers' experiences (Murphy & Dingwall, 2007).

My role as an instrument in the ethnography demanded continuous reflexivity to uphold research quality (Angrosino, 2008). As a novice researcher, I had multiple lenses through which to reflect that of a researcher, nurse and foreigner. These were both a benefit and a challenge in conducting the research. Despite efforts to be unobtrusive, my presence was noticeable, posing benefits and challenges. My presence in the hospital sparked curiosity, fostering rapport with caregivers and healthcare workers. Building rapport is crucial in ethnography, making participants feel valued (Fetterman, 2010). Nurses occasionally sought insights into hospital care practices in my home country (Ireland) and sought confirmation about their practices in Vietnam. I provided insights into care standards without making definitive conclusions about resource differences. Striking a balance between researcher and nurse roles occasionally led to conflicts, influencing my reactions to clinical practices and interactions (Gobo, 2008). Interactions with healthcare staff were marked by discomfort at times, notably in smaller patient rooms, requiring adjustments in translation practices such as during patient review. I also assisted the informal caregivers with small tasks such as holding a personal belonging or opening a window.

My characteristics as a foreign medical person in the hospital were met by some patients with expectations of change or improvement in their care. I was always clear to indicate that I was there as a PhD researcher and had no influence over the clinical care received. Having a background as a nurse and being an infection control advisor also required that I navigate some degree of perceived suspicion about the purpose of my role as 'inspector' of the hospital. I offered reassurance that none of the data gathered was being provided to any authorities and that the specific hospital and participants would be fully de-identified prior to thesis submission and publication.

My perspective and view as a nurse and global health professional inevitably shaped the research (Gobo, 2008). While my insider understanding of hospital activities added depth to the data, the unfamiliar context in Vietnam and the language barrier created an outsider's perspective. I acknowledged and clarified my assumptions at the research's outset, recognising that cultural nuances explained by the translator were approximations (Fetterman, 2010). I conducted briefings with the translator after interviews and observations to address this. A second Vietnamese translator reviewed transcriptions to ensure an accurate representation of the data.

4.8 Ethical approval

The study proposal underwent ethics approval by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University (see Appendix 13 for the detailed ethical approval form. Additionally, ethical approval was sought from the hospital's institutional review board in Hanoi, Vietnam. This required presenting the project to a hospital ethics panel, defending its design and submitting translated versions of all documentation in Vietnamese (see Appendix 14).

4.8.1 Informed consent

For consent to be considered informed, participants had to be fully aware of the intent of the research, its effect, the absence of any direct benefits, the potential risk of psychological distress or intrusiveness in their daily lives and have the opportunity to express their autonomy and withdraw from the study at any time (Alaei et al., 2013).

During observation periods, written consent was obtained from informal caregiver participants (see Appendix 15). A qualified medical interpreter facilitated conversations to obtain consent. Consent for observation periods with informal caregivers was secured at the start of each session. It remained valid unless the participant chose to withdraw, the patient was discharged, died, or transferred to another facility. In ethnography, consent is often negotiated over time, and for this study, no participants withdrew (Gobo, 2008).

An opt-out consent method was employed for individuals present in the public hospital unit but not directly involved in the study (see Appendix 16). Ethnographic research, which involves observation of multiple subjects, practices and actions in naturalistic settings, distinguishes between ‘principals’ with research consequences and ‘spear carriers’ with peripheral involvement (Murphy & Dingwall, 2007). Opt-out consent is a pragmatic approach for obtaining consent during ethnographic observations (Vellinga et al., 2011).

An informational poster with opt-out details was displayed in the hospital. The translator verbally confirmed opt-out preferences with family members at the patient's bedside during observation periods, noting and excluding those who opted out. These ensured people could opt out by providing text numbers to ensure their choice was not violated (Hammersley, 2006b).

For interviews, informal caregiver and healthcare worker participants' written consent was obtained (see Appendix 17). All participants undergoing interviews had the opportunity to review the study information booklet and were provided with a printed copy at least 24 hours in advance of the interview. Conversations facilitated by a Vietnamese translator were conducted in person. Participants were informed of their right to revoke participation anytime during the interview or within six months afterwards, with the provided contact details.

4.8.2 Confidentiality

Participants were informed about confidentiality and how this would be upheld throughout the research.

Interviews were recorded using a TASCAM digital voice recorder, and audio files were transferred directly to a secure university drive at the end of each day of data collection. The translator was fully informed about confidentiality and signed a confidentiality agreement at the start of the research. Transcription was performed by the Vietnamese translator, who directly transcribed each interview into Vietnamese and translated the text into English. Interviewees were allocated identification numbers, and personally identifiable data was removed from the transcripts and kept following Lancaster University guidelines. Participants were given a choice of interview location: a private room in the ward or at the patient's bedside. In the emergency room, there was no private room available for interviews, so informal caregiver interviews were not conducted at this location.

4.8.3 Right to withdraw

Participants were encouraged to withdraw or opt out freely, facilitated verbally by the translator in the hospital. No interview participants withdrew, although some chose not to engage initially, opting out of observations.

4.8.4 Harm and benefit

Explicit consideration for any potential harmful psychological consequences or exploitation the participants may have endured by participating in this study was considered (Rubin & Rubin, 2005b). While it is generally considered that ethnographic research is minimally intrusive into participants' lives, there is potential for harm.

This research could have presented a stressful situation for caregivers who were likely already under increased stress due to the illness of their relative. Ethnographic observations can change the behaviours of those being observed, who may feel they are being ‘examined' or having their activities evaluated (Atkinson & Hammersley, 1994). Overt observation may cause discomfort or self-consciousness. To address this, I endeavoured to build a rapport with participants and ensure inconspicuous placement in the clinical unit was prioritised. Participants were provided contacts for reporting any study-related discomfort, as outlined in the participant information sheet.

This research may have raised participants' expectations for improvement in the patient's clinical care or in their situation as informal caregivers. It was made explicit to the participants that there were no direct benefits to engaging in this research. A voucher for a meal from a hospital food vendor was available to all persons undergoing an interview by way of thanks. However, no other reward or financial incentive was offered.

The research is cautious not to disclose the specific hospital to prevent potential harm. Publications recognise the sensitivity to criticism in Vietnamese culture, where criticism of health system improvement can be unwelcome. Emphasis is placed on international comparisons to avoid portraying individual failures and to support a no-blame culture in hospital improvement efforts.

Foreigners in Vietnam generally enjoy an esteemed status and ensuring that the participation of the healthcare workers was voluntary and not coerced by my foreign status or the hospital administrator's authority was important to continually assess. This was mainly achieved through verbal communication and assurances from participants and offering assurance of their autonomy to participate in the research and withdraw at any point up to six months after data collection.

As part of the ethics process, developing a lone worker policy and conducting a risk assessment were necessary to ensure it was safe for me to conduct this research (see the ethics application in Appendix 18). In a hospital environment, it could reasonably be anticipated that I would witness sub-optimal patient care practices leading to hospital-acquired infection transmission or other adverse patient outcomes. In my researcher's role, participant as an observer, I had decided not to intervene if non-evidence-based clinical practice was observed unless it presented an immediate threat to the patient's life. However, no such practice was observed, and reflection on observed clinical practices was maintained in the reflexive diary.

In reflecting on potential harm, considerations included the colonial origins of ethnography and the risk of reinforcing negative power stereotypes. To mitigate this, I emphasised a participant-observer role characterised by mutual respect and knowledge exchange. Maintaining trust and providing ongoing feedback to the hospital, including progress updates, dissemination and sharing with relevant entities, remains a priority beyond the thesis lifecycle.

4.8.5 Data storage and management

Data storage is aligned with the University of Lancaster policy. Field notes taken during participant observation periods and during interviews, which were initially in paper format, were typed up by me at the end of each day of observation. These and a personal reflection diary were maintained using MS One Note and accessed through a password-protected computer. All data, including audio files of interviews, fieldnotes and consent forms, were stored in a locked safe with only me having access. All electronic data, including transcripts, field notes and audio files, are stored on a password-protected computer on the university's cloud storage. The medical translator signed an agreement to maintain the confidentiality of the participants and the transcripts throughout the study. The transcript data was analysed using NVivo qualitative software, and in the short term, interview materials were housed in this programme on a password-protected computer. All files had a consistent system of naming files applied by me to ensure the organised structure of documents for easy retrieval. Data was stored on Lancaster University’s Box, a cloud storage facility with enterprise-level file servers, authenticated identity access management, a data loss prevention index and additional user encryption. Box is accessible from an individual password-protected computer. In the longer term, the data will be destroyed following examination for a PhD thesis.

4.9 Quality and rigour

Maintaining quality throughout the research process was essential to ensure the findings were robust enough to contribute to the body of literature, knowledge and practice. Guba and Lincoln (1989) offer a framework for ensuring rigour in qualitative research, which includes authenticity, inclusive representation of stakeholders, feedback of findings, participant empowerment and training of participants to act on their behalf (Guba & Lincoln, 1989). The criteria they proposed for assessing the rigour of qualitative research are credibility, dependability, confirmability and transferability (Forero et al., 2018; Nowell et al., 2017).

Credibility aims to establish the internal validity of the research to have confidence in the truth of the findings. In qualitative research, this means that the findings of the study accurately represent the experience of the participants (Nowell et al., 2017). Recognising the inherent subjectivity in qualitative data, I employed various strategies to enhance credibility. These included triangulating information from different sources, engaging in debriefing sessions with peers and participants, maintaining persistent observation and sustaining prolonged engagement throughout the research process. To further validate my findings, participants were provided with verbal summaries of topics discussed during the interviews, allowing them to confirm the accuracy of their representation. Additionally, select transcripts were shared with my PhD supervisors for thorough discussion during supervision meetings. These measures contributed to the credibility of my qualitative study (Mays & Pope, 1995a).

I used a reflexive diary as a crucial tool for ensuring the quality of my qualitative data, which is a standard practice in ethnographic research, enhancing the study’s rigour (Atkinson & Hammersley, 1994; Dixon-Woods et al., 2012). This approach explicitly revealed and addressed my assumptions and prejudices by consistently monitoring the construction of interpretations derived from collected data (Atkinson & Hammersley, 1994; Dixon-Woods et al., 2012). In the reflexive diary, I documented decision-making processes, actions and reflections on personal assumptions, ultimately contributing to the credibility of my research findings.

In my study, I addressed transferability, emphasising the external validity of the research findings and their applicability in various contexts (Dixon-Woods et al., 2004; Forero et al., 2018; Nowell et al., 2017). To enhance transferability, I provided comprehensive descriptions of the research context and thick descriptions were incorporated to facilitate judgement by others seeking to apply the findings in different locations (Guba & Lincoln, 1989; Nowell et al., 2017). This approach offers insights into my research's potential transferability, which is discussed further in later chapters and underscores the importance of conducting similar research in diverse contexts.

In my study, dependability was achieved by employing techniques such as method triangulation and a dependability audit and focusing on examining the process of data collection and its accuracy (Forero et al., 2018; Guba & Lincoln, 1990; Nowell et al., 2017). The research process was scrupulously documented to maintain logic, traceability and clarity (Nowell et al., 2017). I audited the research process to provide evidence of theoretical and methodological decisions and the rationale for these choices, contributing to the systematic nature of the research process and ensuring dependable findings (Sandelowski et al., 1997). To enhance dependability, sections of the data, including observations, field notes and the reflexive journal, were provided to my PhD supervisors for review. They actively engaged in reviewing transcripts and the coding structure during supervision meetings. Continuous communication regarding the rationale behind decisions further strengthened the dependability of the research, with explicit presentation of decision-making throughout the thesis.

In my study, achieving confirmability was essential for ensuring the objectivity of the research and minimising researcher bias. Confirmability is intricately linked to credibility, transferability and dependability, all contributing to the neutrality of findings (Guba & Lincoln, 1989). The reflexive diary played a pivotal role in maintaining confirmability by facilitating critical inquiry into decisions and providing a rich contextual understanding of the research environment (Bryman, 2001). The reflexive accounts provided throughout this chapter are heavily drawn from the reflexive diary to enhance the trustworthiness of the research. This study has aimed to demonstrate adequate quality and rigour and avoid research bias.

4.10 Data analysis

Analysis-focused ethnographic data requires the researcher to engage in an iterative, cyclic and self-reflective process as preliminary interpretations are challenged, and data is continually revisited to plan for further data collection to generate new insights into the data (Higginbottom, 2004; Pope, 2000). The process is characterised by the identification and classification of the data, which then progresses to generalisations and, ultimately, interpretation and explanation of patterns (Borbasi et al., 2005a; Dixon-Woods et al., 2012; Fetterman, 1998; Higgenbottom et al., 2013). In this research, the data I collected includes ethnographic observations and interviews, supplemented with field notes and a reflexive journal. Additional media included photographs of the hospital units, plus a map of their layout was also used to provide contextual understanding throughout the analysis. These were analysed using Roper and Shapira's (2000) framework for thematic analysis, which has been successfully applied to the analysis of focused ethnography (Higgenbottom et al., 2013; Higginbottom, 2011; Higginbottom et al., 2015; Roper & Shapira, 2000). This approach is systematic, transparent, relevant to this methodology and compatible with NVivo software for qualitative data analysis (Higginbottom et al., 2015; Roper & Shapira, 2000).

4.10.1 Coding for descriptive labels

Interviews were transcribed in full in Vietnamese and translated into English by a qualified medical translator (see Appendix 19). A list of infection prevention and control terms was translated into Vietnamese to minimise misunderstanding between terms during translation (see Appendix 20). Observations were recorded in English and uploaded in their original format. The initial coding did not include supplementary raw materials such as field notes, maps and reflexive journals. The first step of the analysis was to conduct the first level of coding of data into broad categories and reduce this information into descriptive labels. In thematic analysis, codes are used to identify a feature of interest in the data, and coding is the first step in organising the data into meaningful groups (Boyatzis, 1998). Initial codes were derived from the data rather than approaching the data with a priori codes. Transcripts were imported into NVivo, and relevant parts of the text relating to potential themes were coded using the node function in the software. The same piece of text was often coded multiple times under different nodes where it could relate to multiple future themes. Identifying codes commonly found in observations and interviews indicated those codes most frequent across the data for descriptive labels.

4.10.2 Sorting for patterns

The descriptive labels were sorted for patterns into smaller subsets to identify codes that show data patterns that are alike and unalike. These patterns or themes describe a concept that captures a meaning important to the research question (Boyatzis, 1998). These emerging patterns fit the data and help explain reoccurring relationships (Boyatzis, 1998; Higgenbottom et al., 2013). There is a degree of subjectivity in deciding what qualifies as a theme within the analysis. Some researchers rely on the prevalence, while others rely on assessing the relevance of the data to the research aims (Braun & Clarke, 2006). For my research, a flexible approach was most appropriate, and patterns were identified through frequency and aligned to the research question. The codes in NVivo were reviewed based on their relationship to other codes to develop these patterns. Corresponding data extracts within these patterns were collated and viewed under the theme (parent node) or individual code (child node). A hierarchy using node levels in NVivo facilitated the distinctions between overarching themes and subthemes within them.

4.10.3 Identification of outliers or negative cases

Several codes did not fit within the main patterns and themes identified during this process. Data that did not easily fit or were very infrequently mentioned were identified as outliers. They were used to test the rest of the data.

4.10.4 Generalising with constructs or theories

Generalising themes with theories and constructs can strengthen the data analysis through the identification of the relationship of the data with existing constructs and theories. In this study, a further level of coding was performed using the World Health Organization's core components of the infection control model (see **Figure 1.1**) and health system framework (see **Figure 4.1**).

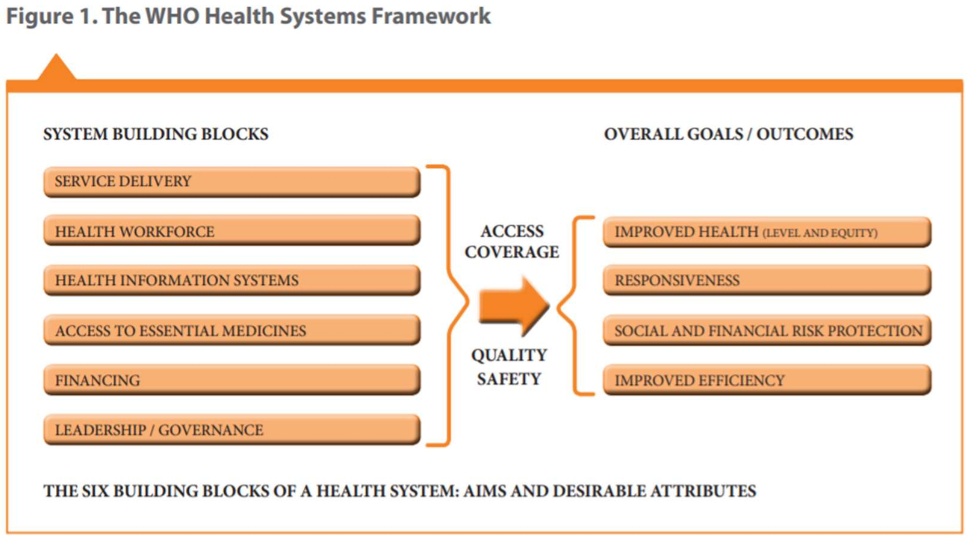


Figure 2.1: The World Health Organization's health systems framework (World Health Organization, 2010, p.3)

Initial codes were reviewed and refined when viewed through the lens of these frameworks. As a result of this process, several themes were separated where they did not form clear patterns, and others were reconceptualised. Themes were reviewed and refined within the data and cross-checked against the research questions and often the original transcripts to ensure they reflected each participant's experience. Each theme was named, and short summaries were developed to describe the key points in each theme. Data analysis was an iterative process that required constant refinement throughout the research process. Complex relationships between existing themes were identified.

4.10.5 Memoing, including reflective remarks

Throughout the analysis process, my reflections and memos were included. When ideas or insights about the data occurred, I noted these down. While not objective data, it facilitated the building of connections between themes and facilitated a deeper analysis of the data at various stages throughout the cyclical analysis process (Higgenbottom et al., 2013; Iedema et al., 2015; Roper & Shapira, 2000).

4.11 Conclusion

In this chapter, I have described the research design and conduct process, providing a comprehensive overview of the chosen methods and their implementation. The next chapter will present the findings, offering insights and analyses derived from the conducted research.

5 Findings

In this chapter, I describe the study sites and present the findings.

5.1 An account of the study location

The study site was a 1,200-bed general hospital providing inpatient, outpatient, and specialist treatment within a district health authority in a city in Vietnam. The hospital employs over 1100 staff, conducts over 13,000 surgeries annually, and has a close-to-capacity occupancy rate, catering for approximately 45,000 patients annually. The four departments where I conducted this research were (1) emergency, (2) general medical, (3) neurosurgery and (4) orthopaedics, and I provide an account of each below. My first impressions of the hospital were that it presented a distinctive contrast to the typical landscape of UK healthcare facilities; notably, the predominantly younger patient demographic, the long durations of admissions and the fact that healthcare staff were notably less visible in comparison.

5.1.1 Emergency department

The ward's layout was a single, expansive space designed to accommodate up to 25 patients, supplemented by a temporary cot bed strategically placed in the corridor to cater for an additional patient. The proximity between beds was notably narrow. An isolation room was allocated for patients with infectious diseases or utilised as a private space for those who opted for paying accommodation. The corridor, consistently bustling with human traffic during all observation periods, served as a thoroughfare within the department.

During the observational periods, the meeting room remained unoccupied, except when the staff utilised it as a break room or accessed supplies from the adjacent storage area. The nurse's station was the focal point for healthcare workers' interactions, contributing to elevated noise levels throughout the department. A singular bathroom was shared among all patients and informal caregivers. At the same time, the unit featured four sinks – two located within the patient toilet, one positioned at the nurse's station, and another in the private room. Hand sanitisers were conveniently positioned at the end of many beds. Despite the absence of a designated space for informal caregivers, their presence was evident as many either occupied plastic chairs beside the patient's bed, sat at the foot of the bed, or even lay on mats on the floor beside the patient's bedside. This nuanced description captures the intricacies of the emergency department's physical layout and dynamics.

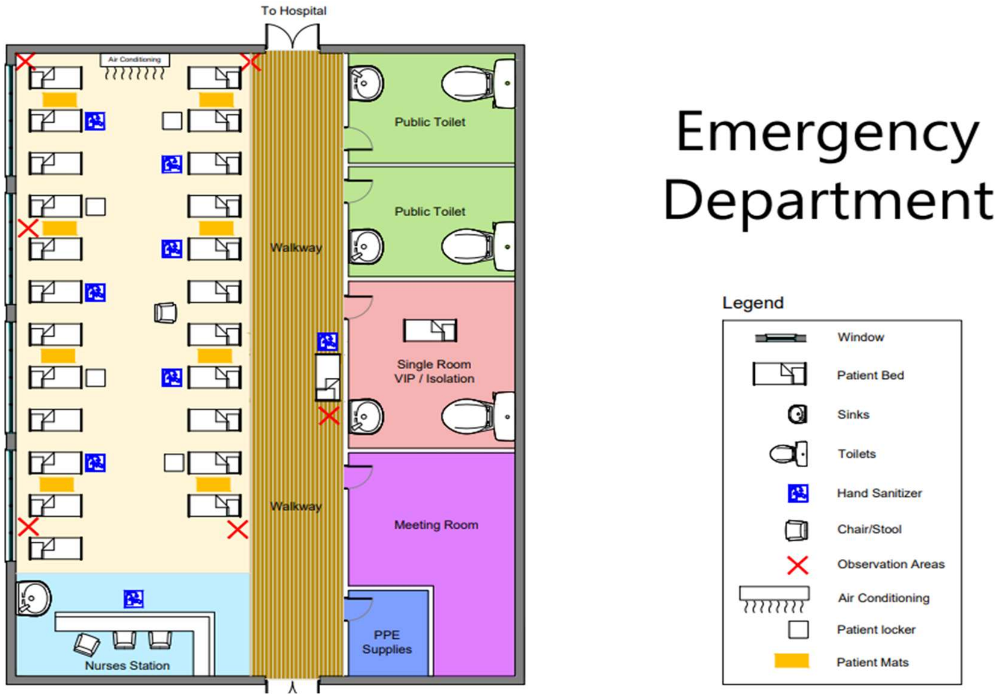


Figure 5.1: Emergency department layout

5.1.2 General medical department

The general medical department had a spacious layout, accommodating up to 50 patients. Private patient bays lined the left side, except for the bay nearest to the nurse's station, which was dedicated to critically ill patients. Notably, there was no specific isolation area. A multifunctional nurses' area served as an office, conference room, patient file storage and staff lunchroom. The department featured four toilets with sinks: one public, one reserved for paying private patients and two in larger closed bays. Hand sanitisers were strategically placed in corridors and patient bays.

Despite the absence of air conditioning, all bays were equipped with windows. Informal caregivers had no designated space; instead, they occupied chairs beside the patient's bed or lay on floor mats.

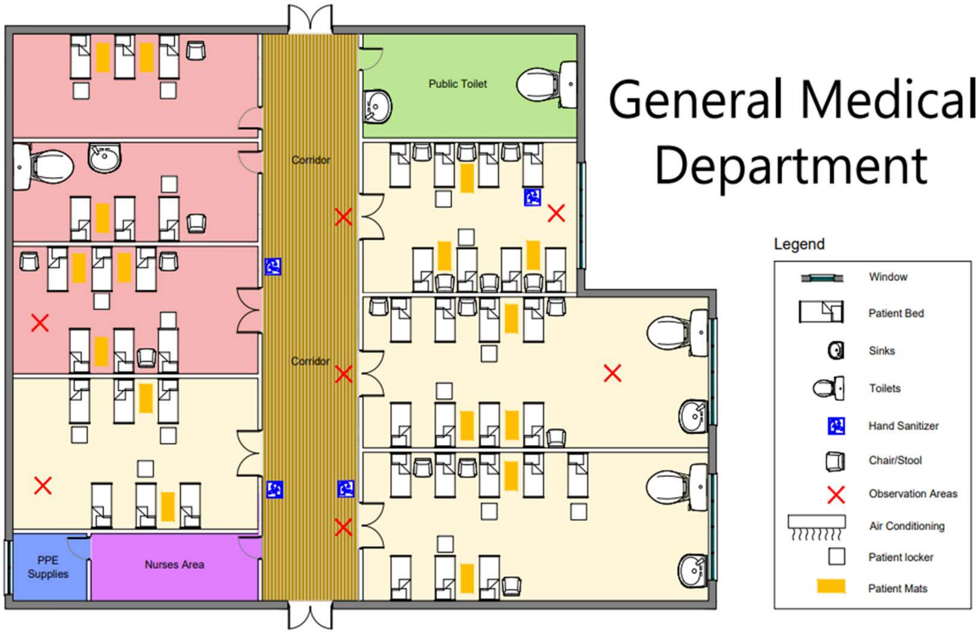


Figure 5.2: General medical department layout

5.1.3 Neurosurgical department

This ward, with a capacity of 34 patients, felt cramped. Notably, there was no designated isolation room, and ongoing construction at the department's front added to the sense of limited space. The nurse's station served a dual purpose, functioning as a workspace and a storage unit. The department featured three bathrooms and sinks – one public and two within the patient bays. Hand sanitiser was readily available in the patient's bays. Despite the absence of air conditioning, each bay was equipped with windows. Informal caregivers lacked a designated space and typically occupied chairs beside the patient's bed or rested on floor mats alongside. This detailed portrayal captures the confined atmosphere of the department, emphasising its ongoing construction, spatial constraints and caregiver dynamics.

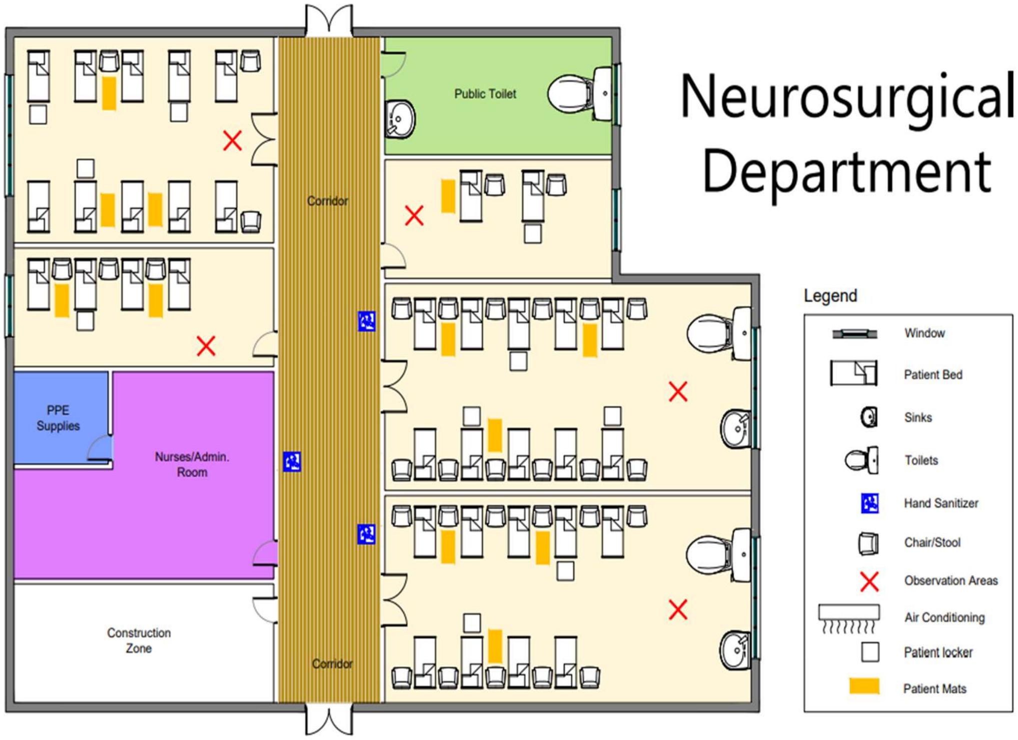


Figure 5.3: Neurosurgical department layout

5.1.4 Orthopaedic department

The orthopaedic department was identical to the general medical department described above.

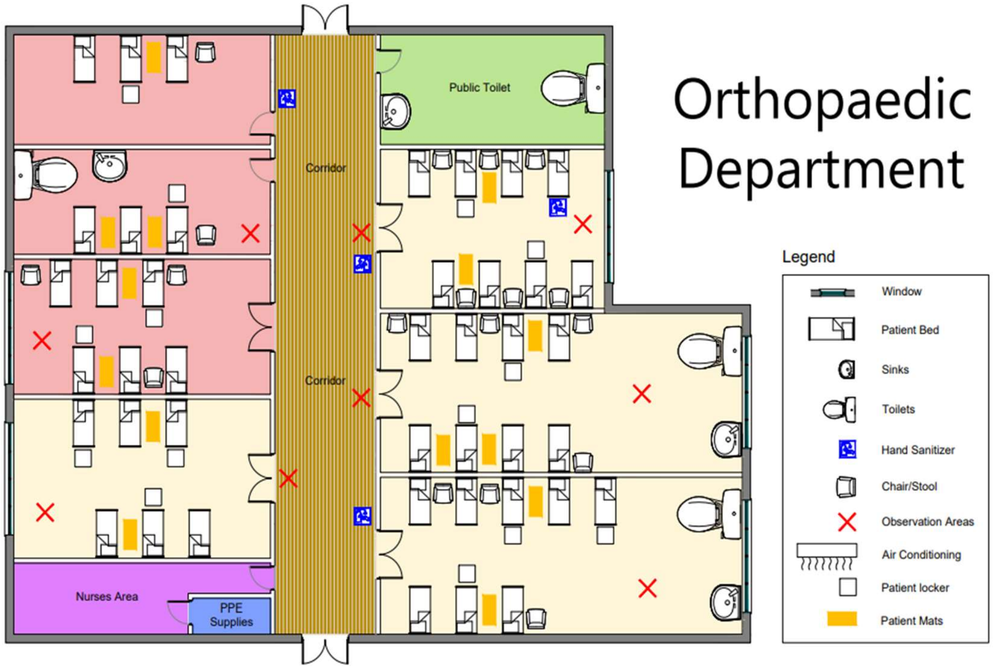


Figure 5.4: Orthopaedic department layout

5.2 Data collected and study participant characteristics

Over four intermittent weeks, I actively participated in participant observation for a total of 32 hours. This included ten hours of observation in neurosurgery, eight hours in general medicine, and six hours in the emergency department, with each observation period lasting one hour. The multi-bed layout typical in Vietnamese hospitals allowed for the simultaneous observation of multiple caregivers during each period. My presence was consistently mobile within a bay of an individual ward throughout these observation periods.

I conducted 25 interviews, 13 involving informal caregivers and 12 with healthcare workers. Six informal caregiver interviews and four healthcare worker interviews took place within the neurosurgical unit. I did five interviews in general medicine with informal caregivers and healthcare workers. I conducted two informal caregiver interviews in orthopaedics and one health worker interview. No interviews with informal caregivers were conducted in the emergency room, but two interviews with healthcare workers were conducted. **Table 5.1** presents the aggregate data collected and the characteristics of the participants interviewed.

Table 5.1: Data collection and participant characteristics

Data Collected	Clinical Area	Hours
Observation hours	Emergency	6
	General medicine	8
	Neurosurgery	10
	Orthopaedics	6
Interviews	**Clinical Area**	**Number**
Informal caregiver interviews	Emergency	0
	General medicine	5
	Neurosurgery	6
	Orthopaedics	2
Healthcare worker interviews	Emergency	2
	General medicine	5
	Neurosurgery	4
	Orthopaedics	1
Interviewed Informal Caregiver Participant Characteristics		**Number**
Informal caregiver type	Family	9
	Commercial	2
Informal caregiver gender	Male	3
	Female	6
Primacy of role	Main caregiver	7
	Secondary caregiver	2
Duration of informal caregiver role	Minimum	4 days
	Maximum	12 years
	Median	9 weeks
Interviewed Healthcare Worker Participant Characteristics		**Number**
Healthcare worker type	Nurse	11
	Doctor	1
Healthcare worker gender	Male	1
	Female	11
Median duration in role (years)		6 years

Throughout the data extracts, participants are identified via an alphanumeric code using IC (informal caregiver) or HCW (healthcare worker), followed by ED (emergency department), GM (general medicine), ORTHO (orthopaedics) and NS (neurosurgery), and then participants are numbered sequentially by the department.

5.3 Overview of themes

The overarching themes are presented in **Table 5.2**.

Table 5.2: Findings overview

Theme	Sub-themes
The embedded roles of informal caregivers in the healthcare ecosystem	• Professionalisation of the informal caregiving role • Recognition in national policy • Interdependence: Healthcare workers' reliance on informal caregivers • Navigating challenges: unsustained informal caregiver support
Informal caregivers as proxy healthcare workers in infection prevention and control	• Caring gestures: The spectrum of patient care tasks • Hands-on engagement: Informal caregivers in direct patient care • Unseen care: Informal caregivers in indirect patient care • The domestic nexus: Informal caregivers occupy the hospital space • Collaborative threads: Collective cooperation among informal caregivers
Navigating the duality: Informal caregivers' role in infection prevention and control as challenge and opportunity	• Hospital landscape: The context of infection prevention and control • Rituals of safety: Observed infection control practices • Comprehending transmission: Informal caregivers' perspectives on disease and their role in infection control

	- Boundaries and barriers: Constraints impacting infection control practices

5.4 Theme 1: The embedded roles of informal caregivers in the healthcare ecosystem

Informal caregivers play an integral role in delivering patient care in Vietnamese hospitals. The professionalisation of their role, cultural endorsement and acknowledgement in national policies and societal expectations underscore their significance. Despite this, they remain peripheral to the formal health system, encountering obstacles in obtaining sufficient support for ensuring safe patient care, including infection control measures.

5.4.1 Professionalisation of the informal caregiving role

Two categories of informal caregivers were identified, family and commercial caregivers, as shown in **Table 5.1** above. Family caregivers were most common and were motivated by a cultural expectation of familial duty to undertake their caregiving role:

> *Firstly, it is because of the custom of Vietnamese people. Specifically, the children always want to take care of their parents when they are sick and hospitalised. It's all about the filial duty in a family*. IC-NS-6

Commercial caregivers were distinguished from family caregivers through payment for their caregiving services, which could be short term for a specific hospital admission or longer term at home, shifting to the hospital as needed. Both commercial caregivers interviewed had been caring for their patients before hospital admission. Shifting demographics in Vietnam, including governmental policy limiting family size and women working outside the home, underpinned the trend towards commercial caregiver use:

> *Let me explain a little bit. In the past, Vietnamese parents had many children, but now we just narrow down to one or two children. And the children are very busy with their work to earn a living, you know. Hence, if*

> *their financial health is good, they can hire commercial caregivers to look after their parents*. HCW-GM- 2

Employing a commercial caregiver is an extension of family care and considered compatible with Vietnamese cultural expectations when a family member cannot be personally available:

> *To me, it's totally fine [to hire a commercial caregiver]. They still show their filial duty. There are many ways for us to show the responsibilities with our parents, you know. As long as we don't forget them*. HCW-GM-3

In contrast to family caregivers, commercial caregivers were motivated by a sense of occupation and the need for gainful employment to undertake their caregiving role:

> *To be honest, everyone has his or her own job. Well-educated people will work for state agencies. That's one way of making money. This is my job. This is how I earn a living to raise my children and support for my family. I have worked as a professional caregiver for 12 years and had quite a lot of experience in looking after patients*. IC-GM-6

The commercial caregiver role is part of the Informal labour market in Vietnam. Nurses in some hospital units maintain an unofficial list of informal caregiver contacts. Gaining entry to that list is desirable by commercial caregivers because of the financial rewards but challenging:

> *But you know, not every commercial caregiver can come here [to the hospital] and work. If you want to work as a caregiver in this hospital, you need to be in a network and win the nurses' favour. For me, because I often take care of my patients at their houses when they are still strong and come along if they are sick and have to come to the hospital. I'm not in the list of caregivers that the hospital will provide to the patients. For those caregivers, they are paid 20 to 25 USD per day. I just get 200 USD per month*. IC-NS-5

5.4.2 Recognition in national policy

The Vietnam Ministry of Health's national hospital administration policy outlines provisions for informal caregivers in Vietnamese healthcare institutions. The patient care system follows a tiered structure: level one (most critical, surgery, intensive care), level two (high dependency units and emergency room) and level three (least critical, general medicine/surgery). This hierarchy involves a decrease in the need for nurse supervision at levels two and three, coupled with an increase in expectations of the informal caregiver's role in patient care:

> *In fact, the role of caregivers is very important in level 2 and level 3 care. They are like our right hands. However, for level 1 care, the nurses will provide the full care to the patients and cannot rely on anyone*. HCW-Ortho-2

I gathered my data in a level two care department, specifically the emergency room, and in level three departments (orthopaedics, general medicine and neurosurgery), where informal caregivers were more prevalent. The recognition of informal caregivers in national policy was exclusively mentioned by healthcare workers in my research, with informal caregivers unaware of the policy.

5.4.3 Interdependence: Healthcare workers' reliance on informal caregivers

The reliance on informal caregivers as a key component in the overall functioning of the hospital was apparent:

> *In fact, the caregivers play a crucial role in Vietnam. There are two reasons for this. Firstly, we have less nurses compared to other countries. Secondly, the patients always outnumber the nurses and we don’t have optimal supportive facilities to provide full care to our patients. For patients that require special care such as ones in emergency room, post-operative room and ICU, the nursing care will be completely delivered by us. For patients with more stable health status, we rate the care as level 2 and 3. For level 2, it’s the combination between nurses and caregivers. The caregivers will*

> *share the nursing care with the nurses under the instruction of the nurses. For level 3, almost all the caring tasks will be completed by the caregivers*. HCW- NS-4

Healthcare workers had an embedded framework of delegating less critical patient care to informal caregivers due to their heavy workload, high patient load and administrative burdens. Collaborating with informal caregivers was necessary from the healthcare worker's perspective to facilitate oversight of the patient's condition. Healthcare workers expected informal caregivers to comply with hospital norms and regulations, which was a source of conflict where they perceived informal caregivers overstepped the scope of their role by not adhering to their instructions. From the informal caregiver perspective, they identified their role as more concerned with patient comfort and well-being and felt they could more accurately anticipate patients’ needs as they knew them best:

> *I expect the caregivers to understand the health status of the patients. In addition, it is better if they can track the physical and mental recovery of the patients. I know it’s really hard for them to have good knowledge like us, the nurses. It’s down to the fact that the Vietnamese people always want to take care of their relatives who are hospitalised. However, sometimes, we are not so satisfied with their compliance. Even though we explain things the family members do not care about that*. HW-NS-4

Healthcare workers perceived the role of the commercial caregiver differently from that of the family caregiver, indicating they found their competence and working relationship superior:

> *Yes. The commercial caregivers have better understanding about procedures in the hospital. Moreover, they are more professional in looking after the patients than the normal [family] caregivers, whom we have to instruct about even the smallest task.* HCW-GM-2

In the setting, I found the dynamics between nurses and informal caregivers revealed tensions stemming from healthcare workers' positional authority and the caregivers' cultural deference. Nurses sought compliance with their instructions and adherence to hospital rules from informal caregivers, influencing the practical aspects of the caregivers' resources to fulfil their roles:

> *We used to propose the hospital's leaders to equip one patient bed with one hand sanitiser. However, many incidents have occurred. I don't [want] to speak ill of the caregivers, but many caregivers have bad awareness. We used to try to attach one bottle of hand sanitiser to every two beds, but the caregivers often bring back to their home after the patients are discharged. It's very hard to control them.* HCW-ER-1

Healthcare workers' perceptions of informal caregivers contributed to a palpable sense of disempowerment and marginalisation experienced by the informal caregivers. They noted that interactions with healthcare workers were not consistently positive or supportive. In certain instances, the tension between different groups emerged due to overlapping duties, especially between clinical nurses, leading to disputes regarding the delegation of tasks considered traditionally within the nurse's domain. During interviews, healthcare workers expressed little worry about informal caregivers potentially making their roles obsolete, as they believed caregivers lacked the same level of expertise in fulfilling these duties:

> *Let me tell you this. The Ministry of Health is moving toward the satisfaction of the patients. Specifically, they come to the hospital and we have to satisfy them like in Chinese, Taipei or Singapore, where the nurses provide comprehensive care, even the most basic task like feeding or doing personal hygiene, to the patients. That's why the caregivers cannot replace us. No, never. The caregivers can support the level 3 patients in terms of nutrition and some basic task under our instruction and education, but they can never replace us for sure*. HCW-ORTHO-1

5.4.4 Navigating challenges: Unsustained informal caregiver support

Informal caregivers were concerned by the quality of patient care they delivered and expressed an interest in enhancing their competency. The expectations set by healthcare workers were unclear to informal caregivers, who lacked proper training to meet these standards. Their skill acquisition primarily occurred through observation or verbal instructions provided by healthcare workers:

> *They only told me to keep clean everything so that my daughter in law could recover soon and nothing bad happened to her. That's it. So I work and learn from my experience. No one shows me how it should be done or provides me any training. I want to learn more about how to look after my daughter in law*. IC-GM- 8

Similar concerns extended to commercial caregivers, who also revealed they had received no formal work training. One caregiver specified her specialisation in elderly care, acquired through years of hands-on experience rather than formal training:

> *I haven't been trained in any specialised classes like nurses and doctors here. However, I have learned everything by watching with my own eyes what the doctors and nurses in the hospital do to take care of their patients*. IC-GM-6

Healthcare workers consistently overestimated the extent of formal training provided to informal caregivers, a perspective not aligned with what the caregivers themselves reported. While healthcare workers believed informal caregivers were deviating from guidance, the caregivers insisted they had never received any guidance. In interviews, healthcare workers expressed concerns about informal caregiver competence and asserted that weekly health education sessions, in addition to on-the-job instruction, were conducted for patients and caregivers. However, informal caregivers either lacked awareness of these educational sessions or reported they did not occur, yet they acknowledged the value of ad hoc informal instruction from nurses. Throughout my data collection, I did not witness any educational sessions, and the scheduling of such sessions remained unclear:

> *If I have an opportunity to get some lessons about taking care of patients in the hospital, I'm more than happier to take it. I have been here for 9 weeks by now and I have not known of any education sessions. Yes, its true*

> *the nurses will tell me how to do some things, mostly they like to tell me when I am doing something wrong so I can adjust my practices.* IC-GM-7

Healthcare workers acknowledged a responsibility to educate informal caregivers but lacked time to fulfil this role due to their demanding workloads and job constraints. Consequently, despite the recognised importance of supervision and education, the feasibility of providing adequate training was limited within the existing constraints:

> *…for the teaching the caregivers, in the ministry regulation, it says that we have to do that but we have no time to do that, here, we have a lot of patients, today I have more than 20! How can we possibly get the time*. HCW-NS-1

Moreover, healthcare workers viewed the caregiving patterns of informal caregivers, involving multiple individuals rotating throughout the day to care for a single patient, as an additional obstacle to delivering comprehensive training. I observed in my field notes that having multiple caregivers heightened the risk of infection transmission, posing potential threats to both the patient and the caregivers. This dynamic also pointed to an increased risk, extending to the communities where the caregivers returned.

Despite being explicitly acknowledged in national health policy, informal caregivers were not regarded as integral members of the health workforce in the hospital. The formal recognition of their presence did not translate into providing education, training, or access to infection control supplies. Additionally, the hospital's reliance on their role was less prominent than the assumed significance of their presence for cultural obligations.

5.5 Theme 2: Informal caregivers as proxy healthcare workers in infection prevention and control

Informal caregivers were involved in numerous tasks spanning direct and indirect patient care. To provide a contextual background for later discussions on infection control risks, I delineate their involvement in direct patient care tasks in this sub-theme. Informal caregivers constitute an integral part of the hospital's ecosystem and have created distinct physical and social subsystems within the hospital setting. As I show in the findings, the hospital takes on characteristics akin to a domestic space. Notably, subsystems involving collective, cooperative support among networks of informal caregivers are discernible within this hospital environment.

5.5.1 Caring gestures: The spectrum of patient care tasks

Informal caregivers mainly assist patients in performing their activities of daily living, and these patient care tasks can be categorised into direct and indirect care. **Table 5.3** defines this distinction between care types, and **Table 5.4** identifies the tasks and frequency with which these care practices were observed.

Table 5.3: Definition of direct and indirect patient care

Direct patient care	All patient caregiving activities required informal caregivers to be in direct physical contact with the patient, patient secretion/excretions or medical equipment used at the patient's bedside.
Indirect patient care	Caregiving activities that did not involve direct patient contact or contact.

Table 5.4: Observed patient care tasks performed by informal caregivers

Direct Patient Contact	Number of times observed	Indirect Patient Care	Number of times observed
Feeding	42	Serving food and drinks	31
Wiping patient’s mouth after eating	36	Washing utensils	21
Providing fluids	35	Changing TV station	19
Emotional support – hand holding, comfort touch, kissing	32	Arranging patient’s clothes	19
Moving patient into bed	21	Cleaning plastic bowls	16
Assist patient with toileting	18	Washing clothes	12

Touching/manipulating an intravenous line	14	Looking for nurses and doctors	11
Assisting patient with dressing	13	Buying food, medicines, outside supplies	8
Assisting patient with hygiene, showering	11	Fanning patient	6
Assisting patient with slippers/shoes/socks	11	Changing bedclothes	5
Wiping patient's forehead	9	Pushing patient on a trolley	4
Combing patient’s hair	9	Cleaning lockers and bed surroundings	3
Rearranging pillows in bed	8		
Massaging patients’ body	7		
Assisting patient with mobilising to the bathroom	5		
Assisting patient with swallowing medication	5		
Assisting patient with hygiene in bed	4		
Support for physical therapy (moving legs)	2		
Changing patient's wound dressing	1		
Applying nebuliser, holding it in place	1		
Emptying urinary catheter	1		

In reviewing the spectrum of patient care tasks performed by informal caregivers, it was apparent that their role extends beyond basic caregiving functions to activities with direct implications for infection control. Table 5.4 categorizes observed caregiving practices into direct and indirect patient care tasks, highlighting the frequency and type of involvement that informal caregivers have in patient care. Direct care tasks, such as assisting with toileting, wound dressing, intravenous line manipulation, and emptying catheters, place caregivers in contact with bodily fluids and medical equipment, which can serve as vectors for infection transmission. These actions, though necessary for patient well-being, inherently involve infection risks, particularly when performed by caregivers who may lack formal training or awareness of infection control protocols.

The indirect care tasks, while not involving direct patient contact, also play a role in the infection control landscape within the hospital. Activities like washing utensils, cleaning personal items, and handling linens or other personal items have the potential to spread pathogens if not done with proper infection control practices. The absence of structured guidance for these indirect tasks raises concerns about cross-contamination, especially in shared spaces or when caregivers move between patient rooms and communal areas.

5.5.2 Hands-on engagement: Informal caregivers in direct patient care

I observed informal caregivers engage in 285 instances of direct patient care, many of which posed a potential risk of disease transmission. Notably, high-risk activities observed involved contact with blood, bodily fluids and invasive devices and included patient care tasks such as urinary catheter emptying, nebuliser therapy, wound dressing and manipulation of intravenous lines. In interviews, nasogastric feeding was also reported but not observed. I observed that informal caregivers frequently manipulated intravenous lines, primarily adjusting the drip rate, but they sometimes manipulated the cannula dressing on the patient's body. These actions caused frustration among healthcare workers:

> *Some caregivers are quite knowledgeable or come to the hospital very often, so they tend to change the drip rate of the IV fluid even though the nurses have already adjusted it at a proper rate. You know, I'm, sometimes, busy and need to go out. When I come back, I see that the caregivers have already changed the rate so that the drip can go faster.* HCW-GM-4

In my field notes, I documented:

> **Field notes:** *It is hard to distinguish where the nurse's role ends and the informal caregiver begins. It is also easy to understand why the caregivers do a lot of this work; a health worker is nowhere to be seen to request to do any of these tasks. It is concerning to observe risky practices without the safeguards of any infection control training materials. It makes me curious about this context's true hospital-acquired infection rate. It appears to be*

> *very much the norm and tolerated for informal caregivers to be deeply involved in the daily patient care here.*

Other direct care tasks involved nutrition support, dressing, mobilisation and patient massage. The more severely ill the patient, the more bedside care was observed for that patient, including wiping mouths, helping to move in the bed, turning the patient and assisting in giving medication:

> *She needs my help to wash, feed, and go to the toilet. I also wash her body, make sure she is happy, call the nurse when she needs and help her take her medications, all of this I am responsible for*. IC-GM-10

I witnessed instances of direct physical contact during emotional support for the patients, encompassing gestures such as holding hands, kissing and placing the head on the bed beside or on the patient's body. The close physical proximity of the caregivers was explained in interviews as a means to alleviate patient anxiety and positively impact the patient's overall mood.

5.5.3 Unseen care: Informal caregivers in indirect patient care

I observed informal caregivers providing a total of 155 episodes of indirect patient care, which are outlined in detail in **Table 5.4**. This included contact with the patient's environment, cleaning bedside areas and bathrooms, and changing bed linen. These indirect care activities, while often overlooked, play a critical role in infection prevention and control, as caregivers maintain the cleanliness of the patient's immediate surroundings, which reduces potential infection transmission.

> *I still take extra precautions with some things like bowls, chopsticks, the restroom, and bed of my dad. For the bowls and chopsticks, I use hot water to wash them and dry them out on a shelf right away*. IC-GM-9

Caregivers' attention to maintaining a sanitary environment demonstrates their implicit role in infection control, even though they receive no formal training. Through these practices, informal caregivers often act as proxy healthcare workers, performing tasks that would typically fall under the remit of trained hospital staff. Field notes also reflected the high level of engagement informal caregivers had in infection control even when unrecognized by the hospital staff. For example:

> *Field notes: Informal caregivers frequently handle items around the patient's bedside, like bed linens, clothing, and utensils. They were observed wiping surfaces and arranging patients' belongings in an orderly manner, which seems to reduce clutter and may play a role in minimizing infection risks. In one instance, an informal caregiver carefully wiped down her mother's bed rails and placed a towel to catch any spills, indicating an awareness of cleanliness as a protective measure.*

In addition to patient-centered tasks, informal caregivers regularly left the ward to purchase food, fetch water, and bring additional supplies from home. This mobility raises an additional infection control concern, as caregivers often interact with various individuals outside the hospital and bring items from potentially unsanitized environments. Reflecting on these challenges, one caregiver remarked:

> *"When I return, I wash my hands and clean the things I bring before going near him." (IC-GM-7)*

The routine presence and involvement of caregivers in tasks related to patient hygiene, such as changing bed linens and cleaning the surrounding area, align them closely with healthcare support roles. As noted in field observations:

> *Field notes: In one instance, a caregiver took it upon herself to clean the shared bathroom area after seeing other caregivers use it. She brought a towel and cleaned the surfaces before leaving, seemingly aware that the cleanliness of shared spaces affects the health of all patients and caregivers in the ward.*

In addition to cleaning, some caregivers were observed preparing materials for use, as healthcare workers might do in a formal care setting. For instance, several caregivers arranged the patient's supplies, checked on linens, or adjusted pillows and sheets in preparation for doctors' rounds, mirroring the work done by hospital aides.

> *Field notes: One caregiver was seen setting up her mother’s bedside for the doctor’s visit, ensuring that all medical supplies, linens, and personal belongings were organized and accessible. Her actions displayed a level of readiness akin to hospital staff preparing for patient assessments.*

5.5.4 These actions highlight the need for structured infection control guidance. Although informal caregivers may intuitively perform basic sanitation, formal instructions on practices such as hand hygiene, proper waste disposal, and handling potentially infectious materials could enhance their role in infection control. The unseen work of informal caregivers contributes significantly to maintaining a clean hospital environment, underscoring their valuable role in infection prevention within the hospital setting. **The domestic nexus: Informal caregivers occupy the hospital space**

Informal caregivers engulfed the hospital spaces due to their number and the long durations, often months, of their presence day and night. The daily trappings of life were visible throughout the hospital units, and it became a domestic space where the lives of informal caregivers were underway:

> **Field notes***:* *Informal caregivers outnumber the patients in this small space. Some are rolling up their patient sleeping mats, one is doing her morning tai chi exercises standing by the window of the unit, another is clipping her nails, another is on the phone, and yet another has just emerged from the shower in the unit. This shower is shared with the patient. It appears to be like a community hostel for informal caregivers in many ways. The ward is loud and hot, and caregivers speak to each other and their patients. Breakfast is over; two caregivers enter the bathroom to wash out their basins. All the patient beds have personal linen on them – these are blankets and pillows brought in from home. The informal caregivers store their patients' sleeping mats under their beds. In fact, under the patients' beds are multiple large bags of supplies, clothes, linen and other items to stock the patients' stay. It feels less like a hospital and more like a hostel because of the absence of any healthcare worker.*

I noted the crowded spaces and shared sanitation facilities between patients and informal caregivers and the potential risk of infection transmission. While healthcare workers acknowledged the potential infection risk associated with the presence of informal caregivers, it was not their primary concern. Instead, their frustration emanated from the conversion of the clinical space into a domestic one and the complex interrelational dynamics, which took precedence over infection control considerations:

> *It is because they often lay out everything like a mess and don't respect the doctors and nurses when we visit the patients. There are so many caregivers in the patient room and it's hard for us to request them to leave the room. We understand that they are very worried about the health status of their relatives, but they have to listen to us, right? The patients need a clean environment to avoid infection, but the caregivers always mess everything up. You know, if we remind them too much, they will think that the nurses are dissatisfied with them and have some unwanted reactions. So I got to say that it's very difficult to work as a nurse*. HC-NS-2

Informal caregivers were unhappy with the hospital conditions based on discomfort rather than infection risk, noting a lack of space, beds and access to sanitation facilities. Where possible, they paid privately for improved facilities, two to four bedded units, some with air conditioning, television and bathrooms with hot water. Colloquially, these were referred to as 'VIP' rooms:

> *First of all, I would like to have a VIP patient room, it means that we will have the bathroom, the hand hygiene sink and more space where I can store our thing and for me to sleep and so on, for example, here, if I want to wash the face of my wife, I have to go out, to go to other rooms to ask for the hot water. The condition are more difficult in this room, but I do not have the financial situation to allow me to pay the expensive fees for a VIP room or which we have to pay an extra fee of more than 5 USD/day.* IC-GM-10

5.5.5 Collaborative threads: Collective cooperation among informal caregivers

I observed that informal caregivers spent a great deal of time waiting for healthcare workers' attention to receive clinical care for their patients. Nurses had intermittent contact with patients every few hours or daily, and doctors were visible mostly during daily medical rounds. Many patients were admitted to the hospital for months at a time, and discharges were regularly delayed for weeks due to health insurance bureaucracy. This extended hospital stay fostered enduring camaraderie among informal caregivers, creating a robust support network in the absence of healthcare workers. Informal caregivers supervised, assisted, and often intervened with the care of other caregivers' patients, contributing to infection prevention and control in ways resembling the responsibilities of formal health workers.

These acts of cooperation were frequently observed and included tasks that carried infection control implications. For example, caregivers would remind each other to wash hands after handling soiled linens or help clean up spilled fluids to prevent contamination in shared spaces. Through these interactions, caregivers demonstrated an intuitive understanding of infection prevention, often learning through observation rather than formal instruction.

> *Field notes: Observing the dynamic between informal caregivers, it is communal, cooperative, and almost collegial. There appears to be an informal system among them where, when one informal caregiver needs to leave the ward to get food, medication, or address another issue, they casually ask another caregiver to keep an eye on their patient. Time again, these small collectives of caregiving are evident, with an informal caregiver going to help out another caregiver’s patient by giving them a drink or making them more comfortable in bed. They seem to feel responsible for each other. Though not formally trained, I witnessed one caregiver reminding another to use hand sanitiser after helping a patient with toileting, hinting at a shared awareness of basic infection control practices.*

In one instance exemplifying this collegiality, numerous informal caregivers responded to an alert for help in the emergency room. The caregivers collaborated instinctively to help stabilize the situation until a healthcare worker arrived.

> *Field notes: In an instant, a hive of informal caregivers descended on the patient’s bed, where seconds earlier, an informal caregiver had given a call out for help. The monitors the patient was connected to were alarming. At least four informal caregivers nearby came to assist the informal caregiver and patient. One caregiver immediately began adjusting the bed while another attempted to comfort the patient, asking if he was in pain. Two other caregivers took on a more logistical role, locating and guiding the nurse to the patient. These caregivers displayed teamwork, responding as quickly and efficiently as a trained health team might in a time-sensitive situation.*

Another notable example of collective action was when a caregiver noticed that a shared bathroom had become visibly unsanitary, posing an infection risk. This caregiver took it upon herself to gather cleaning supplies, involving two other caregivers, who helped clean the area. While not specifically trained in infection control, the caregivers' collective actions effectively contributed to maintaining hygiene standards within the hospital environment.

> *"We look after each other’s patients if one of us has to go somewhere. If I see something dirty, I clean it because it affects us all." (IC-GM-11)*

In these interactions, informal caregivers displayed a shared sense of duty and collaboration that contributed to infection control. By collectively maintaining cleanliness and watching over each other’s patients, they helped reduce infection risks in ways akin to healthcare aides. The social bonds they formed enabled a functional, if informal, system that filled gaps in formal infection prevention practices, highlighting their role as proxy health workers in the hospital. These findings suggest the potential for enhancing infection control practices by leveraging this collaborative network among informal caregivers.

5.6 Theme 3: Navigating the duality: Informal caregivers' role in infection prevention and control as a challenge and opportunity

I found that the participants did not universally understand the concept and practice of infection prevention and control. There were conflicting findings about the status of a functional infection control system within the hospital, providing insight into the conditions in which informal caregivers operate. The infection control practices I observed being performed by informal caregivers and healthcare workers are presented here to contextualise the discussion around the informal caregiver's role as part of the more extensive infection control system. I also present informal caregivers' insights into disease transmission and their perception of their role in infection control. Constraints to their role were evident throughout the findings.

5.6.1 Hospital landscape: The context of infection prevention and control

Healthcare workers offered insights into the hospital's infection prevention and control status, perception and understanding, providing a context for the overall environment of informal caregivers. Their knowledge levels varied, presenting a conflicting view of infection control functioning at the hospital. While overall understanding of disease transmission was good, four healthcare workers were unfamiliar with the term ‘infection prevention and control’ in Vietnamese, although they recognised related practices. All healthcare workers understood ‘hospital-acquired infections’, but when probed further, some demonstrated a lack of understanding of its characteristics. Clinical nurses exhibited superior infection control knowledge, while administrative nurses, handling discharge planning and health insurance administration, were more familiar with the hospital's infection control organisation.

There was conflicting information from healthcare workers on the existence of an infection control unit at the hospital. The prevalence of hospital-acquired infections was similarly unclear; most were unsure, and others mentioned a prevalence range from 1% to 3%. Surveillance practices were not well known; however, a head nurse offered:

> *The infection control department is still doing a research on a daily or monthly basis. I mean they provide us with a form and we will stick in it if there is an infected patient. We then inform them about that. The staff of the infection control department come here every day for infection examination and control. That staff will collect information day by day from a doctor and a nurse in my department. If an infection case is detected, we will collaborate with them to decontaminate the patient room*. HW-NS-2.

Hospital-acquired infections were deprioritised in clinical practice and were intrinsically linked to a culture of blame. There was a perception that hospital-acquired infections were insignificant:

> *You can see that I have been working here for 20 years and every year, normally I meet about 3 to 5 cases in my years here, it may be hospital infection, maybe which occurs after a surgery or wound or something like that but normally it is very very rare here*. HW-GM-5

This extended to a similar perception of the prevalence of antimicrobial-resistant pathogens in the hospital:

> *It is compulsory for the patients to have pre-operative and post-operative antibiotics if they have surgeries, at least for 15 days. We have few cases of multidrug resistance here, but very few, less than five per year, I think it is because of the good practices of the nurses and doctors in this hospital that affliction does not trouble us too much*. HW-ER-2

Bolstering these perceptions was nurses' lack of access to laboratory information systems for culture results to determine the presence of a hospital-acquired infection and a misconception that the high temperatures and humidity of the Vietnamese climate prevented infections.

A culture of blame shaped healthcare workers' practices and attitudes towards informal caregivers and infection control practices. Healthcare workers mentioned that if a hospital-acquired infection was present, it was likely contracted before a patient was admitted to their unit, either in another facility or on transfer from another unit where an invasive device was inserted or in the community. Blame shifting to informal caregivers as possible sources of hospital infections was common in all healthcare worker interviews:

> *Because there are many respiratory diseases in this department such TB, it's very easy for them [informal caregivers] to contract an infection. You know, we cannot conclude whether a person is TB positive right away. Sometimes, we can only confirm this fact in the treatment time of the patients. So it's highly likely that the caregivers can bring the infection to the community or brought it here in the first place*. HW-ER-1

Patients and informal caregivers were not typically informed if they had a hospital-acquired infection diagnosis, reportedly to avoid concerning them. No informal caregiver interviewed was made aware of any related diagnosis. During the fieldwork, neither the translator nor I were required to wear personal protective equipment in clinical spaces; however, shoe covers were provided in the emergency and neurosurgical departments:

> **Field notes***: there is no way to know if a patient has a hospital-acquired infection. There are no signs above the patients' beds to indicate whether any additional precautions may be needed. Personal protective equipment is stored in the nurses' station, rationed for use by healthcare workers, and unavailable to informal caregivers. During one observation period, I learned that we were likely in a room for patients with infectious diseases. I noticed the hospital staff, the doctors in particular, closing the door when they exited the room, which was uncommon after four weeks in the hospital where doors were generally left open. I also noticed the two patients in this four-bed bay. One was a young woman, very unwell and visibly jaundiced, so I had thought perhaps hepatitis initially, but it was dengue season in Vietnam, so that could also have been the cause. The other patient had hepatitis B and verbally told us this during a brief exchange. Their relatives are in close contact with the*

> *patients' blood and bodily fluids, emptying catheters, etc. but have no personal protective equipment.*

5.6.2 Rituals of safety: Observed infection control practices

Table 5.5 presents the cumulative infection prevention and control practices I observed performed by informal caregivers and healthcare workers across all departments.

Table 5.5: Infection prevention and control practices observed

Cumulative Infection Prevention and Control Practices Observed (# of times/person)		
Standard precautions	Informal caregiver	Healthcare worker
Hand washing	2	2
Alcohol hand sanitiser use	5	2
Wearing gloves	0	2
Wearing gown	1	1
Wearing medical mask	0	1
Environmental cleaning (cleaning/ disinfecting environmental surfaces)	2	1
Household waste disposal	7	1
Sharps waste disposal	0	6
Respiratory hygiene/cough etiquette	0	1
Aseptic technique	0	0

Healthcare workers more frequently performed standard precautions than informal caregivers. Informal caregivers reported performing hand hygiene and wearing personal protective equipment much more frequently than was observed. This may have been due to the limited duration and time of observation periods or a reporting bias. I observed many missed opportunities to perform standard precautions compared to the number of patient care tasks performed by informal caregivers reported above.

5.6.3 Comprehending transmission: Informal caregivers' perspectives on disease and their role in infection control

Knowledge of disease transmission underpins the application of standard precautions which are universal work practices to prevent infection transmission. Informal caregivers did not understand the term ‘infection prevention and control’. They claimed not to know about disease transmission but could provide examples and related practices:

> *Yes, I understand, when people are sick they sometimes need to be separated from other people and their things needs to be cleaned and washed, like if they have tuberculosis, this was very common disease in the past and people would have to go away and live in spacious areas so the rest of the household did not become sick.* IC- NS-7

Informal caregivers primarily drew from their life experiences for knowledge rather than from knowledge learned in the hospital:

> *I would like to let you know that I used to be a soldier. So I understand that there are some infectious diseases that if one person has one of these, he or she will easily spread it to other surrounding people such as scabies. It is the same in my family, if my dad catches a flu, he will easily spread it to other members in my family. With my experience, I understand that I have isolate him. If the condition is contagious, we have to separate the bowls and chopsticks of the patient from other members in our family*. IC-GM-8

The faecal-oral transmission route was poorly understood, and it was inaccurately thought to relate to ‘using cold tap water’ instead of hot water for handwashing. Vietnam's hot, humid climate was often mentioned as advantageous for disease prevention. One informal caregiver linked disease transmission to supernatural causes:

> *Sometimes, I think it is better to first see a traditional healer for these health problems, often you can prevent a sickness by wearing a talisman for good luck so that it will not get you. Diseases have many causes, not just physical ones*. IC-NS-6

Informal caregivers recognised they had a role in infection prevention and control but felt that it was minor and unlikely to impact patient outcomes. Principally, informal caregivers conceptualised their role as being guided by healthcare workers, who provided specific instructions:

> *A doctor instructed me that I had to wear gown when I came to this hospital to take care of my daughter in law. If I don't wear the gown, I'm not allowed to enter the patient room. I don't wear mask and gloves, I have not been offered them*. IC-GM-9

Informal caregivers expressed concern over their personal health and the risk of contracting and transmitting infections as a result of their caregiving activities:

> *I just feel afraid of infectious diseases, but it's my job, you know. I have to earn a living to support for my family.* IC-GM- 6

Overall, commercial caregivers believed they followed a more professional approach to infection prevention. They mentioned adherence to hospital regulations, maintaining a separation between their belongings and the patient's, consistently washing their hands and using hand sanitiser. However, I seldom witnessed these reported practices. The segregation of personal items seemed to be more influenced by the absence of familial ties and a more formalised caregiving structure rather than a deliberate infection control measure:

> *And even though I stay here with the patient, I always separate my personal stuffs like clothes no matter how acute her health status is, it is respectful to*

> *her and I aim to please her family so they continue to employ me even after she goes home from hospital.* IC-NS-5

5.6.4 Boundaries and barriers: Constraints impacting infection control practices

Informal caregivers consistently identified constraints preventing them from performing infection control practices related to the physical hospital environment, access to supplies and infrastructure and a lack of mentorship by healthcare workers.

The crowded, cramped hospital rooms had few sanitation facilities, and the overall infrastructure of the hospital hindered infection control practices:

> **Field notes**: *There is an entire absence of isolation rooms for patients in these clinical areas. Based on the hospital layout and design, it appears that the VIP rooms should be the isolation rooms. However, the additional revenue generated by the additional money paid for these rooms, over and above the health insurance costs, seems to have superseded the need to reserve them for patients with infectious pathogens. The proximity of many beds and the interchangeability of informal caregivers going from patient to patient make this an optimum environment for an outbreak.*

Basic supplies, including ways of drying hands, hand sanitiser and personal protective equipment, were unavailable. Informal caregivers used their cloths for hand drying. Hand sanitiser availability varied by unit, and bottles were often empty. The use of personal protective equipment by informal caregivers was uncommon even when it would be expected, such as changing a bedpan:

> **Field notes:** *The lack of any discernible infection prevention and control supplies and equipment in the ward is striking. It could be a home or non-clinical space as it lacks typical hospital features. In this eight-bed bay, there are no hand washing facilities. I see no hand sanitiser, no personal protective equipment of any sort. Even if an informal caregiver wanted to practice infection control, there are many challenges to doing so – the infrastructure and environment are not designed to support these*

> *practices. One informal caregiver, a young man, has his pocket hand sanitiser, which I have seen him use twice during this one observation period. The closest sink is out of the bay, down the end of the corridor near the ward's exit. It is an unreasonable distance, not only for informal caregivers, but I wonder how patients can wash their hands or teeth with poor water access.*

Healthcare workers reported they instructed informal caregivers to wear personal protective equipment but conceded the hospital could not provide it. Informal caregivers reported that it was their responsibility to provide personal protective equipment should they wish to use it:

> *When I provide care to any patients, I usually ask their relatives to provide me with necessary equipment and devices for safety reasons. For some tasks like dressing the patient's wound after taking out the needle of IV line, I have to go directly to the administration department and ask nurses to give the cotton sanitised with alcohol. I never enter this room to get such kinds of stuff without prior permission to avoid infection*. IC-NS-5

I identified healthcare workers' absence of consistent role modelling and mentorship in performing standard precautions as a constraint. I observed instances where healthcare workers did not adhere to standard precautions, including lapses in hand hygiene, not wearing personal protective equipment and using the same set of gloves for multiple patients. Healthcare workers acknowledged their responsibility in ensuring infection control practices among informal caregivers but expressed limited control over their access to supplies and the standardisation of precautions they adopted:

> *I would be happy to do more and learn more about how to do these things to keep my child safe but I don’t see the nurses doing these things- how can I learn if they do not show me*. IC-ORTHO-2

5.7 Conclusion

In these findings, I highlighted informal caregivers' crucial role in infection prevention and control through their direct patient engagement. I identified risk factors for infection transmission, including challenges with supplies, infrastructure and knowledge. Cultural dynamics, such as the relationship between healthcare workers and informal caregivers, the perceived undervaluation of informal caregiver contributions and societal expectations influenced these factors. In the next chapter, I will explore the implications of these findings and place them within the context of existing research.

6 Discussion

In this chapter, my findings are discussed and situated within the broader literature, drawing on theoretical models to explain their positioning. I discuss the strengths and limitations of the research with recommendations for further research policy and practice and a conclusion.

6.1 Summary of findings

In the findings, I identified the key characteristics of informal carers in Vietnamese hospitals, emphasising their professionalisation, cultural alignment and societal expectations of the role. Two categories exist: family carers motivated by familial duty and commercial carers providing paid services. National hospital policies acknowledge the significance of informal carers and accommodate their presence by reducing nurse supervision at less critical patient care levels. The interdependence between healthcare workers and informal carers, driven by staff shortages and high patient loads, creates tensions. The informal carers expressed concerns about the quality of care they were providing and their desire to enhance competence, yet they faced challenges due to unclear expectations and minimal training. Despite informal carers' explicit recognition in national health policy, they are not fully integrated into the healthcare workforce.

I have explored informal carers' extensive involvement in direct and indirect patient care and found that many of their activities pose an infection control risk. The carers were engaged in a spectrum of patient care tasks, including both direct and indirect activities, with instances of high-risk actions such as handling bodily fluids. The presence of informal carers transformed the hospital into a communal quasi-domestic space, leading to overcrowding and the sharing of facilities, thereby creating infection control challenges. The hospital environment was frustrating for health workers and informal carers alike. In my findings, I have highlighted the collaborative threads and camaraderie among informal carers that form a support network without consistent healthcare worker attention. This informal network eases caregiving burdens but increases infection transmission potential. It underscores the complex dynamics and challenges of integrating informal carers into the healthcare system.

I have identified disparities in the understanding, practices and challenges in infection prevention and control between healthcare workers and informal carers. Healthcare workers demonstrated diverse knowledge levels, with clinical nurses exhibiting superior infection control understanding compared to administrative nurses. Blame-shifting towards informal carers as potential infection sources was common among healthcare workers. Patients and informal carers were rarely informed of hospital-acquired infection diagnoses. Discrepancies between reported and observed infection control practices among participants highlight the need for improved education and consistency. Informal carers possessed varying levels of understanding of disease transmission, often relying on information from their lived experiences and colloquial knowledge. Constraints such as the hospital's physical environment, supply shortages and inadequate infrastructure hindered healthcare workers’ abilities to implement infection control measures. Addressing these disparities is crucial for improving infection control systems and supporting informal carers in similar healthcare settings.

My findings underscore informal carers' significant role in patient care, infection control challenges and the need for improved support and education in Vietnamese hospitals. In addition, they highlight the intricate interplay between cultural norms, healthcare policies and infection prevention in the hospital context. In this chapter, my findings are discussed and situated within the broader literature, drawing on theoretical models to explain their positioning. I discuss the strengths and limitations of the research with recommendations for further research policy and practice and present a conclusion.

6.2 Discussion of findings

The role of informal caregivers in infection control within Vietnamese hospitals is a complex and multifaceted issue, deeply intertwined with the culture, the health system and infection prevention and control factors. In this discussion, I explore various patterns and relationships within the data, contextualise my findings with references to previous research and identify unexpected results while considering alternative explanations.

In Chapter 5 of this thesis, the findings on the roles, practices, and challenges of informal caregivers within Vietnamese hospitals present several unique contributions to the existing literature. This study supports and extends existing research on informal caregiving in low-income healthcare contexts, which has acknowledged the significant, yet often unstructured roles caregivers play in patient care, particularly where healthcare staff and resources are limited (Islam et al., 2014; Stewart et al., 2020). Previous articles have also noted how cultural norms influence informal caregiving roles, which aligns with the findings here that cultural expectations shape caregiver roles in Vietnam, especially in the delegation of certain infection control tasks by healthcare workers (Hadley et al., 2007; Hui et al., 2013).

However, there are few articles that specifically address informal caregivers' role in infection prevention and control in hospitals in Vietnam or comparable settings. Although some international research has observed infection control behaviors in caregiving roles in hospitals, there remains a gap in the literature that specifically addresses how the lack of formal training, resources, and support directly affects infection control in these hospital settings. Notably, the informal transformation of hospitals into quasi-domestic spaces by caregivers, as observed in this study, is unique in the literature on infection control.

This study also adds to the broader understanding of infection control by offering insight into how informal caregivers navigate complex hospital dynamics without formalized guidance. Addressing this gap would benefit from future articles focusing on caregivers’ direct impacts on infection transmission rates, the effects of formal infection control training programs for caregivers, and, more broadly, comparative studies to confirm whether similar dynamics exist in other low- and middle-income healthcare systems.

6.3 This thesis uniquely contributes to the field by highlighting the pivotal but under-recognized role of informal caregivers in infection prevention and control within Vietnamese hospitals. Unlike prior research that primarily focuses on healthcare workers' practices, this study provides a nuanced view of informal caregivers as essential yet overlooked actors in infection control, bridging critical care gaps in low-resource hospital settings. By documenting the caregivers' extensive involvement in both direct and indirect patient care activities—and the infection risks these pose—this study adds valuable insight into the ways informal caregivers navigate infection prevention challenges, largely unsupported and untrained. This research also underscores the importance of cultural context, revealing how societal norms and power dynamics between caregivers and healthcare workers shape infection control practices in ways that have not been fully explored in existing literature.Informal caregivers as integral yet overlooked contributors in healthcare systems

The indispensable role of informal caregivers in healthcare systems, particularly in low-income countries, is underscored by their significant contributions to patient care despite operating on the periphery of official recognition (Islam et al., 2014c; Makoae, 2009; J. Y. Park et al., 2020; Söderbäck & Christensson, 2007). Aligned with prior research and the systematic review presented in Chapter 2, informal caregivers emerge as crucial contributors to patient care, engaging in both direct and indirect caregiving activities (Hadley et al., 2007; Islam et al., 2014). This nuanced caregiving is vital for addressing a spectrum of patient needs that might otherwise go unmet within the constraints of officially available hospital services (Stewart et al., 2020). the substantial role of informal caregivers, showcasing their involvement in tasks ranging from basic daily activities to complex medical care and demonstrating the breadth and depth of their contributions (Carroll et al., 2016; Hessels & Larson, 2016; Van Buijtene & Foster, 2019). Informal caregivers often bridge gaps left by formal healthcare services, providing a continuum of care that extends beyond the confines of hospital walls (Hadley et al., 2007; Islam et al., 2014). Moreover, the acknowledgement of informal caregivers as contributors to patient care in national policy aligns with global recognition of their indispensable role (Kumah, 2022). In low-income countries, where resource constraints and gaps in formal healthcare services are pronounced, informal caregivers become even more crucial (Cho & Kim, 2006; Kim & Kim, 2021). The role of informal caregivers in low-income countries, as reflected in my research, resonates with and extends the existing body of knowledge, emphasising the need for a comprehensive understanding of informal caregivers' contributions in regions where formal healthcare resources are limited.

Embracing a systems thinking lens rooted in systems theory provides a conceptual framework to highlight the integral role of informal caregivers within the broader health system. This health system, viewed as a cohesive entity characterised by interconnected and interdependent parts working collaboratively, emphasises the intricate relationships among various components (Xia et al., 2017). This systems lens perspective suggests that enhancing the role of informal caregivers, an essential yet unrecognised component of the system, can result in positive changes in the overall healthcare system, ultimately improving health outcomes (Kirk et al., 2007). Drawing from systems theory, which defines a system as a cohesive entity with interconnected parts fulfilling a shared purpose, the lens of 'holism' aids in understanding the relationships and interactions between system components (Hassan et al., 2020; Meyer & O'Brien-Pallas, 2010). Recognising informal caregivers as integral components within this system allows for a comprehensive perspective on infectious disease transmission within the healthcare system, aligning with the principle that strengthening one part of the system can lead to transformative improvements in the overall health system (Hassan et al., 2020; Germain, 1978; Meyer & O'Brien-Pallas, 2010).

Within the healthcare system, power relations between informal caregivers and healthcare workers emerge as a crucial aspect, influencing infection control practices and patient care. These power dynamics constitute a significant constraint, with healthcare workers exercising authoritative power over informal caregivers, shaping compliance with hospital norms (McGilton et al., 2012; Savundranayagam et al., 2012). The resulting disempowerment, marginalisation and limited access to essential resources and training contribute to a complex mix of power relations (Hudson et al., 2013; Ferrell et al., 2012). Drawing from Western-centric power theories may not fully capture the intricacies of cultural norms within Vietnam, where dimensions like gender, ethnicity and race can play pivotal roles in shaping power dynamics (Aubel & Chibanda, 2022).

At the organisational (meso) level, disparities in power become evident, revealing nuanced differences between caregiver types. Commercial caregivers, often perceived as possessing superior patient care capabilities, wield a different form of collective power compared to the positional power of healthcare workers (Aubel & Chibanda, 2022; McGilton et al., 2012, Weidman, 1988). These power imbalances pose challenges to effective healthcare and infection control practices as informal caregivers navigate advocacy for patient interests while addressing personal power struggles within the hierarchical structure (Aubel & Chibanda, 2022).

On the individual (micro) level, power dynamics manifest in communication barriers and ethical dilemmas, hindering open dialogue between informal caregivers and healthcare professionals (Savundranayagam et al., 2012). The fear of being perceived as challenging professional expertise can lead to conflicts and ethical concerns, potentially overshadowing the best interests of the patient (Hudson et al., 2013). These power struggles, if unaddressed, can directly impact patient outcomes, contributing to burnout and a diminished quality of care provided by informal caregivers (Gaugler et al., 2009).

In navigating these complex power dynamics, strategies such as caregiver education, clear communication protocols and involving informal caregivers in care planning become essential (Ferrell et al., 2012). The interplay of power relations within the healthcare system necessitates a nuanced understanding to develop interventions that promote collaborative and patient-centred care. The complexities within these dynamics further underscore the importance of considering culturally specific factors and a systems thinking approach to comprehensively address power imbalances and enhance the role of informal caregivers within the broader health system (Hosseinpoor et al., 2020).

The incorporation of commercial caregivers into the discourse emphasises the broader reliance on informal caregivers within the healthcare system. Although often an unseen and unregulated cadre, commercial caregivers respond to evolving societal norms, aligning with trends observed in other Asian countries like China and Korea (Hui et al., 2013; Cho & Kim, 2006). Recognising and formalising the role of commercial caregivers could yield substantial benefits for the healthcare system, including skill enhancement, resource allocation, financial incentives and standardised practices. This formalisation can be effectively analysed through a systems thinking perspective, where enhancing this specific component contributes to the overall improvement of the healthcare system (Cho & Kim, 2006; Xia et al., 2017).

As Vietnam undergoes economic development, the caregiving landscape may transform, with commercial caregiving services becoming more widespread. The recognition of commercial informal caregivers in this research underlines the reliance on informal caregivers in general, despite being an unseen and unregulated cadre. Although relatively understudied in Vietnam, commercial caregivers are a response to changing societal norms, particularly with more family members working outside the home. Similar trends of commercial caregiving have been observed in other Asian countries, with Korea reporting a high prevalence of paid caregivers in hospitals (Kim & Kim, 2021; Cho & Kim, 2006).

Drawing insights from China's experience, where a caregiving industry has emerged due to smaller families and fewer available family caregivers, Vietnam's informal use of commercial caregivers could benefit from formalisation. This could involve improving skills, allocating resources, providing financial incentives, standardising practices and integrating an underground workforce into the mainstream healthcare system, akin to practices in China and Korea (Hui et al., 2013; Cho & Kim, 2006). The economic feasibility of such a model, as observed in Korea, may pose challenges in low- and middle-income countries like Vietnam. However, as the country progresses economically, the decline in the availability of family caregivers makes the formalisation and strengthening of commercial caregiver services imperative for the overall improvement of the healthcare system.

This emphasises the need to view the healthcare system as a dynamic and interconnected entity, where all components play a crucial role in influencing the overall effectiveness of healthcare delivery.

6.4 The pervasive influence of culture on informal caregivers' roles in infection control

Culture exerts a profound influence across the findings of my study, underscoring the pervasive influence of cultural dynamics within hospitals and shaping the experiences of informal caregivers within the healthcare setting. The research findings point to the significant impact of cultural factors, both at the national and organisational levels, on the infection control practices of informal caregivers in hospitals. These cultural aspects encompass the patient safety culture within healthcare organisations and highlight inherent challenges in the existing infection control paradigm, which predominantly targets health workers, as well as cultural and contextual barriers that affect compliance with infection control practices.

Culture, in this context, refers to the intricate web of shared values, ideas, concepts and behavioural norms that enable social groups to function effectively (Hudelson, 2004). I adopt a comprehensive cultural lens, considering multiple levels of influence, including the country's overarching culture, healthcare-specific culture, organisational culture within hospitals, subcultures within specific healthcare institutions and the practice of infection prevention and control. In navigating the cultural landscape within healthcare, I draw from Weidman's (1988) conceptual framework due to its efficacy in elucidating individual behaviours within healthcare culture and integrating cognitive and social system lenses. The framework encompasses the cognitive and conceptual dimension, including values, norms, beliefs, and traditions, as well as the social system dimension, comprising roles, the influence of family and community-level actors, strategies, health-seeking patterns, and social networks impacting health status and behaviour (Aubel & Chibanda, 2022; Weidman, 1988).

To contextualise the research findings within the broader national culture and offer insights into the ideologies and values influencing the healthcare system and cognisant of my own Eurocentric lens, I draw from Hofstede's cultural dimensions theory (Matus, 2021). When applied to Vietnam and examined alongside my research findings, this theory sheds light on the power dynamics within hospitals, revealing societal acceptance of hierarchy. This mirrors the authoritative relationship between health workers and informal caregivers in hospital settings (Hofstede, 2011).

This cultural norm directly contributes to the marginalisation of informal caregivers and their limited access to training and essential supplies. Furthermore, Vietnam’s collectivist culture, characterised by interdependence and extended family structures, plays a pivotal role in the prevalence of informal caregivers in hospitals (Aubel & Chibanda, 2022; Weidman, 1988). This cultural context is not adequately addressed by Western-centric models of family dynamics and caregiving roles. Informal caregivers occupy a unique position within the hospital, transforming it into a quasi-domestic space, reflecting broader cultural norms. The emergence of subcultures among different groups of informal caregivers further underscores the collectivist mindset prevalent in Vietnamese society. This nuanced understanding of cultural influences enriches the interpretation of my research findings, the intricacies of power dynamics, caregiving roles and patient safety within the healthcare system.

The intricate interplay between culture and patient safety within the context of informal caregivers in hospitals is a central theme in this research. Various dimensions influence how caregivers interact with their environment and with each other, and how this ultimately impacts patient safety (Matus, 2021; Hofstede, 1980). A patient safety framework is shaped by organised activities that create cultures, processes, procedures, behaviours, technologies and environments in healthcare to consistently and sustainably lower risks, reduce avoidable harm, minimise errors and mitigate harm's impact (WHO, 2021). The organisational culture of patient safety has been empirically linked to improved adherence to standard precautions and appropriate infection control practices, resulting in enhanced patient outcomes (Braun et al., 2020; Carroll et al., 2016; Hessels & Larson, 2016; van Buijtene & Foster, 2019). This research highlights the significance of cultural norms in shaping patient safety outcomes, revealing specific risk factors rooted in cultural dynamics. Team dynamics, communication, the absence of a safety culture, workload, lack of supervision, inadequate supplies, the physical environment and insufficient education and training emerged as critical patient safety risk factors (Lawton et al., 2012). Cultural factors, such as the absence of a safety culture, limited knowledge and accountability, inadequate feedback mechanisms and the absence of policy safeguards against punitive measures, contribute to substantial underreporting of patient safety incidents in certain contexts, which this research confirms (Aveling et al., 2015; Dhamanti et al., 2021). The recognition of cultural influences and power relations in patient safety highlights the need for a nuanced understanding of how cultural factors shape the behaviours and practices of informal caregivers in hospitals, influencing the broader healthcare landscape.

The crux of this research centres on comprehending the pivotal role played by Informal caregivers in hospitals regarding infection prevention and control. Cultural beliefs about the causes of illness, whether rooted in supernatural forces or biological imbalances, play a pivotal role in determining approaches to infection prevention (Hudelson, 2004). This aligns with Weidman's conceptual framework, which underscores the cognitive and conceptual dimension of health culture, encompassing values, norms, beliefs and traditions (Weidman, 1988). Hygiene practices, another crucial aspect of infection control, are deeply intertwined with cultural norms related to personal and environmental cleanliness (Hudelson, 2004). This is reiterated by Aubel and Chibanda (2022), emphasising the importance of understanding cultural practices for effective health interventions. For instance, health workers' hand hygiene compliance largely depends on the behaviour of other health workers, highlighting the role of culture in shaping infection control practices (Lankford et al., 2003).

Furthermore, social norms and customs, such as greetings involving physical contact, contribute to the transmission of infections and necessitate cultural considerations in the implementation of control measures (Hudelson, 2004). The cultural dimension of collectivism or individualism significantly influences the perception of responsibility for infection control, with collectivist societies emphasising community well-being (Hofstede, 1980). Trust in healthcare systems is intricately tied to cultural attitudes, impacting adherence to recommended practices (Gilson, 2003). The cultural competence of healthcare workers and the integration of cultural practices into healthcare protocols are paramount within healthcare settings, shaping the success of infection control measures (Hudelson, 2004). Stigma and discrimination, influenced by cultural attitudes toward infectious diseases, can impede effective infection control by discouraging individuals from seeking testing or treatment (Hudelson, 2004). Traditional healing practices, existing alongside modern healthcare, require culturally sensitive approaches for successful infection control (Hudelson, 2004).

This study has unearthed several barriers to the effective implementation of infection control practices. These barriers encompass the absence of a structured infection control programme, insufficient knowledge and training, and an unsupportive work environment marked by issues like excessive workload, understaffing, facility limitations, high bed occupancy rates and a prevailing perception of low risk concerning hospital-acquired infections. Moreover, the lack of infection prevention and control guidance for informal caregivers poses a challenge. Typically, infection prevention and control guidance is developed in high-income countries and primarily intended for a health worker audience, making its implementation in different cultural contexts problematic. Many Asian countries base their infection and prevention control guidelines on those established in high-income countries, which may not be fully applicable due to socio-economic, demographic, climatic, bacterial resistance, and prescription variations influenced by culture (Zimmerman, 2007; Choi et al., 2016; Ling et al., 2019; Rhinehart et al., 1991). These guidelines rarely address caregivers, particularly in acute care settings, where the role of informal caregivers differs significantly from that in residential or home care settings (Commission on Safety & in Health Care, 2012; NICE, 2011; Hogan et al., 2022). The international infection and prevention control guidance from WHO and the US Center for Disease Control predominantly reinforces the role of health workers in acute healthcare facilities, addressing family members and caregivers only as passive participants or through patient empowerment programmes (Boyce & Pittet, 2002; Carroll et al., 2016; Park et al., 2020; WHO, 2008). There is a scarcity of evidence regarding how healthcare guidance developed in high-income countries can be effectively adapted for low-income countries. While some models suggest the possibility of adaptation, others have shown adaptation of guidelines to be ineffective or inappropriate. A more promising approach may involve generating evidence by clinicians and academics in low-income countries (provided there is a willingness to do so), offering incentives for compliance and capacity-building among cohorts in low-income countries.

There is a future opportunity for strengthening and culturally grounding infection control guidelines targeted at informal caregivers in hospital settings. The utilisation of infection control knowledge among health workers and the provision of related training for informal caregivers were found to be limited in this research. This observation aligns with the existing literature, where infection control education and training have consistently scored poorly in the implementation of the infection control core components, as highlighted in the WHO global survey (Tartari et al., 2021). Effective infection prevention and control are impeded by the insufficient knowledge of recommended practices and the understanding of disease transmission among health workers (Abalkhail & Alslamah, 2022; Geberemariyam et al., 2018; Macharia et al., 1997; WHO, 2002). This lack of knowledge is particularly significant in contexts where health workers serve as influential role models for the behaviour of informal caregivers. A study conducted in rural Indonesia found that nurses valued experiential infection control learning more than knowledge acquired through formal education (Marjadi & McLaws, 2010). It was also observed that infection control knowledge was often shaped by societal expectations, clinical experience and the influence of superiors (Marjadi & McLaws, 2010; Sparke et al., 2020). These points likely extend to the findings of this research, where informal caregivers demonstrated some understanding of disease transmission. Notably, only one participant in this study attributed infection to supernatural causes, whereas in many locations, cultural beliefs encompass multiple explanations for disease transmission, highlighting the cultural influences on infection control (Bardossy et al., 2016). Informal caregivers in this study exhibited an understanding of disease transmission, particularly in relation to their own risk perception of exposure to diseases, with many expressing concerns about occupational exposure. It is well documented in the literature that healthcare workers are at an increased risk of exposure to diseases in the course of their work, ranging from COVID-19 to hepatitis B and C and HIV (Mengistu & Tolera 2020; Noubiap et al., 2013). Similar principles of disease transmission can be applied to informal caregivers who function as proxy health workers, potentially making them additionally vulnerable to disease due to their lack of formal training and access to resources for self-protection. However, it is important to note that no research has been conducted to date that demonstrates the occurrence of occupationally acquired infections among informal caregivers.

In this study, many missed opportunities to implement appropriate infection control measures were attributed to resource constraints within the context. It is worth noting that the level of infection control system implementation has been directly linked to a country's income level (Bardossy et al., 2016; Horton, 2018, Tomczyk et al., 2022). As a result, low- and middle-income countries often bear a higher burden of hospital-acquired infections, resulting in increased morbidity and mortality (Bagheri Nejad et al., 2011; Lowe et al., 2021; Tomczyk et al., 2022). For example, the adoption of the Center for Disease Control’s infection control guidance in an Indonesian paediatric intensive care unit was hampered by poor physical infrastructure, including the absence of sinks, in addition to poor water quality, an unreliable supply, poor storage of equipment and a lack of single-use items, limited microbiology diagnostic facilities and inadequate sterilisation capabilities (Rhinehart et al., 1991). Similarly, the current research identified infrastructural barriers such as the lack of access to bathrooms and sinks, which hindered informal caregivers from practising hand hygiene. These findings resonate with a previous Vietnamese study that identified overcrowding and infrastructural constraints as barriers to complying with WHO's recommended ‘five moments for hand hygiene’ and called for modified guidance to encourage compliance (Salmon & McLaws, 2015; Thuy et al., 2018). Cultural influences also play a significant role, as alcohol-based hand sanitisers have been proposed as an effective solution for hand hygiene in settings with limited access to sinks and water, particularly in many low-income countries (Pittet et al., 2008). However, prohibitions against alcohol use in religions such as Buddhism, Islam and Sikhism have prevented the widespread use of alcohol-based hand sanitisers in some cultures (Allegranzi et al., 2009; Sparke et al., 2020).

Moreover, maintaining recommendations of at least one metre between beds proved impossible at the study site due to the physical layout of the ward, including vacant patient beds, and the presence of informal caregivers who occupied the space (WHO, 2019). Adequate ventilation was also impractical in a hot and humid country where air conditioning was unavailable, and the older hospital design did not allow for proper ventilation. Furthermore, the provision of essential infection control supplies to informal caregivers was not observed in this research, and healthcare workers were rarely seen to use these supplies, reporting infrequent access. This underscores the multifaceted challenges faced in the field of infection prevention and control in low- and middle-income country contexts.

6.5 Strengths and limitations

In this section, I present the strengths and limitations of this research in terms of study design, data collection and analysis (Ross & Bibler Zaidi, 2019).

6.5.1 Focused ethnography characteristics

Focused ethnography has some inherent limitations and has been criticised for being superficial due to the short-term episodic field visits, defined research questions and the researcher's background knowledge of the cultural group (Cruz & Higginbottom, 2013; Higgenbottom et al., 2013; Knoblauch, 2005). For my research, however, it offered a suitable approach aligned with my professional background to address my predefined research question and target an investigation of specific elements rather than comprehensive cultural immersion (Fetterman, 1998; Knoblauch, 2005). The intensity of the data analysis compensates for the short duration of fieldwork, enhancing the depth of the study (Knoblauch, 2005).

6.5.2 Sampling approach

The purposive sampling snowballing approach used in this research has been criticised for lacking a clear definition, implementation instructions and data saturation parameters, raising concerns about potential sampling homogeneity (Allen, 2017; Higginbottom et al., 2015; Miles & Huberman, 1994). To minimise this, the informal caregiver sample in this study was drawn from a hospital rather than a single community, so connections were not based on social characteristics or relationships. I aimed for variability across the domains in the length of caregiving experience and types of illnesses. However, it is important to mention that access to participants was facilitated by hospital administration gatekeepers and health workers, who helped with introductions.

6.5.3 Single study site

While multi-site ethnography is advantageous for capturing diverse perspectives and contextual variations across different locations, I conducted a single-site ethnography (Falzon, 2009). This facilitated a nuanced, rich and holistic account of the culture of informal caregivers in the hospital's successful recruitment of, and rapport-building with, hospital administration and staff who participated in the study (Carroll et al., 2016; Noble & Smith, 2015). My decision to use multi-site ethnnography was influenced by factors such as limited resources, time constraints and the complexity of navigating multiple sites as a solo researcher. This focused approach allowed for an in-depth exploration of the specific cultural dynamics within the chosen hospital setting, providing a detailed understanding of the targeted context.

6.5.4 Data collection was conducted prior to the COVID-19 pandemic

The data collection for this research occurred before the COVID-19 pandemic and, therefore, cannot account for any differences throughout the pandemic or in its aftermath. Disruption to healthcare services may have profoundly impacted the dynamics of informal caregiving in Vietnam. Little published data exists, but it is likely that informal caregivers were reduced in presence in the hospital and were more acutely aware of infection control practices such as social distancing requirements, use of personal protective equipment, bed spacing, limited patient interaction and active case finding (Nguyen et al., 2021). Due to COVID-19, caregivers of cancer patients in Vietnam provided care at home with occasional remote support from the health service and faced multiple barriers to accessing care (Ho, Jenkins, Ta et al., 2021). This is consistent with the international literature on caregivers during COVID-19, who experienced an increased burden due to the inability to travel to hospitals (Carther et al., 2020; Chiu et al., 2022; Picardi et al., 2021).

Despite the COVID-19 pandemic, the presence of informal caregivers in hospitals in low- and middle-income countries is unlikely to cease, given the cultural and resource needs that underpin their role. Previous epidemics, such as the West African Ebola epidemic, saw informal caregivers who would typically be present in hospitals severely restricted from entering. Patients requiring routine care were redirected to private health facilities or stayed in the community, with a majority unable to access healthcare (Gizelis et al., 2017; McQuilkin et al., 2017). Despite this, once the epidemic subsided, health services returned to pre-epidemic practices with informal caregivers present, and they were more critical for patient care post-epidemic due to the disproportionate loss of human resources for health (Squire et al., 2017; Vernooij et al., 2022).

6.5.5 Language and translation

Conducting qualitative research through translators has inherent limitations, including a lack of consensus on terminology, potential misrepresentation of participant perspectives, missing nonverbal communication such as body language, intonation of speech and its meaning, and use of colloquialisms within specific contexts (Squires, 2009). However, a strength of my research lies in the use of interviews, clarifying discussions and interactions in the participants' native Vietnamese language, allowing for full expression of their perspectives. To address potential misunderstandings, I followed Squires' (2009) four strategies, ensuring conceptual equivalence, translator credentials, their role in the research process and adherence to qualitative methodology recommendations (Squires, 2009). Two experienced interpreters, a Vietnamese medical doctor and a professional medical translator, were employed during data collection to enhance trustworthiness. They contributed to a worksheet to ensure the conceptual equivalency of translated terms, and all interviews underwent quality checks for transcription and translation (see Appendix 20) (Clark et al., 2017; Squires, 2009). All interviews were quality-checked for transcription and translation (Clark et al., 2017; Squires et al., 2020). The English transcripts were cross-checked with the medical doctor interpreter to confirm the findings' meaning, ensuring data credibility, conformity and trustworthiness (Clark et al., 2017; Squires, 2009).

6.5.6 Limited access to the research site

My access to the hospital was controlled by the hospital administration, which constrained the study. Initially, I planned for a comprehensive 24-hour observation across clinical units, which was impossible. I anticipated that night-time, with its reduced staffing, might influence informal caregiving practice. Although attempts were made to compensate by inquiring about caregivers' roles in interviews throughout the day and night, reliance on recall introduced a potential discrepancy. In the literature, site access challenges are cited as having been due to administrative hurdles (Vuban & Eta, 2018).

6.5.7 Use of gatekeepers

In conducting fieldwork within a structured hospital environment, the use of gatekeepers was instrumental in facilitating access and recruitment of both informal caregivers and healthcare workers. Hospital administrators and healthcare staff, who functioned as gatekeepers, played an essential role in participant introductions and navigating the complex hierarchy and cultural dynamics within the hospital. However, their involvement also introduced distinct challenges that influenced the recruitment, consent process, and overall data quality.

Firstly, the reliance on gatekeepers for introductions and access to participants raised concerns about sampling limitations and potential biases. The gatekeepers, as part of the hospital administration, could have subtly shaped the participant pool by preferring individuals who were more familiar with the institutional norms or those perceived as cooperative and compliant with hospital standards. This could lead to sampling bias, as gatekeepers may have inadvertently introduced participants whose views aligned with institutional expectations, particularly concerning infection control practices and hospital dynamics. For instance, nurses were more accessible for interviews due to the internal gatekeeper network, resulting in a limited representation of other healthcare roles and perspectives.

The gatekeepers’ involvement also impacted the consent process. Participants—particularly informal caregivers—might have perceived gatekeepers as authoritative figures within the hospital context, potentially feeling obliged to consent to the study due to perceived institutional endorsement. This dynamic could influence participants' willingness to share genuine experiences, particularly any critical views, out of concern for repercussions. Despite steps to communicate the voluntary nature of participation, the hierarchical nature of the hospital environment, reinforced by gatekeeper introductions, may have influenced participants' responses.

However, the role of gatekeepers also had positive implications, particularly as cultural brokers who facilitated rapport and trust with participants, which is critical in ethnographic research. Given the cross-cultural nature of this study, gatekeepers provided valuable guidance in understanding cultural and linguistic nuances within the hospital, which helped in establishing credibility and encouraging more open engagement from informal caregivers and healthcare workers. This intermediary role likely contributed to a deeper initial engagement, which might have been challenging to achieve independently, especially with informal caregivers who might otherwise view an outsider researcher with suspicion.

To mitigate some of the limitations associated with gatekeeper influence, a reflexive diary was maintained, documenting potential instances of gatekeeper bias in recruitment and its influence on data quality. This reflexivity helped to monitor the influence of gatekeepers on the research process. Nonetheless, it is essential to acknowledge that limited autonomy over participant selection and the embedded power dynamics within the hospital setting likely affected the breadth and authenticity of the data to some extent. These factors underscore the complexity of gatekeeper influence, where their role as facilitators also subtly shapes the data quality through participant selection and perceived expectations.

By addressing the dual role of gatekeepers as both enablers and potential sources of bias, this reflection highlights the nuanced impact of gatekeepers on data quality in ethnographic research within hierarchical healthcare settings.

6.5.8 Healthcare worker perspectives were predominantly those of nurses

The healthcare worker interviews I conducted were predominantly with nurses, with only one interview involving a medical doctor. No other cadres were interviewed. This lack of diversity resulted from convenience sampling, as nurses were more accessible in clinical units where I had built a rapport. The scarcity of doctors and other healthcare personnel in these units was evident. My ethnographic observations partially compensated by offering insights into the practices of other healthcare professionals, contributing to the research findings.

6.5.9 Considering the researcher's influence on data analysis

Ethnographic research requires interpretation of the data to produce an account of culture – both a strength and limitation. As the researcher, I carried my biases, experiences, values and beliefs into the study. Balancing the insider and outsider roles, I drew on my international infection control expertise but remained a novice researcher in the Vietnamese context. I aimed to minimise my bias by providing a thick description of the environment, a transparent, structured data analysis and a documentation of themes (Morgan-Trimmer & Wood, 2016). My reflexive journal addressed my preconceptions and feelings, acknowledged my Eurocentric lens, aided the exploration of my reactions and promoted reflexivity (Carroll et al., 2016; Cruz & Higginbottom, 2013; McCabe & Holmes, 2014; Rashid et al., 2015).

6.5.10 Inherent limitations in data analysis due to the nature of ethnographic data

In the pursuit of rigour in data analysis for ethnographic research, I used various strategies, including triangulation, peer debriefing, member checking, thick description and reflexivity (Rashid et al., 2015). Through these efforts, I aimed to enhance the reliability and validity of the findings (Mays & Pope, 2000). However, the inherently unstructured and iterative nature of data analysis in ethnographic research poses both strengths and limitations. While these strategies contribute to the study’s credibility, concerns arise regarding the transferability and generalisability of the findings. The absence of prolonged engagement, a characteristic of focused ethnography, has been a point of contention in the literature (Cruz & Higginbottom, 2013; Higgenbottom et al., 2013; Knoblauch, 2005). Critics express reservations about the reliability, trustworthiness and credibility of the data collected, emphasising the missed opportunity for participants to acclimatise to the researcher's presence in their natural settings (Braaf et al., 2013; McCabe & Holmes, 2014; Wall, 2015).

6.6 Recommendations

Recommendation for policy, practice and research as shown in Table 6.1 overleaf.

6.7 Future studies

To further support the recommendations proposed, additional studies are essential:

1. **Policy and Stakeholder Analysis**: Before implementing caregiver-focused infection control policies, primary research should explore policymakers' views and intentions at local, regional, and national levels to align recommendations with policy goals. A formal policy analysis could clarify existing provisions for informal caregivers and identify gaps that future policies need to address.
2. **Training Program Evaluation**: Longitudinal studies could assess the impact of infection control training programs tailored for informal caregivers, measuring changes in caregiver knowledge, patient outcomes, and compliance with infection control protocols over time.
3. **Exploratory Studies on Cultural Influences**: Ethnographic studies examining cultural norms in caregiving and hospital practices in Vietnam could inform how best to integrate infection control education that respects local cultural dynamics, addressing caregivers' perceptions and informal caregiving networks within hospitals.

Table 6.1 Reccomendations**Table 6.1 Recommendations**

Policy	Practice	Research
Recommendations related to infection control		
Formalising caregiver roles and training in infection control: Hospitals should create clear policies defining the roles and responsibilities of informal caregivers and setting expectations for infection prevention and control. These policies should require informal caregivers to undergo comprehensive training in proper hygiene, the use of personal protective equipment and infection control measures to reduce transmission risks. Regular education and refresher sessions should be provided to maintain compliance.	Implementing caregiver infection control protocols: Hospitals should introduce standard infection control protocols for informal caregivers involved in patient care. These protocols should cover hand hygiene, the correct use of personal protective equipment, environmental cleaning and respiratory etiquette. Additionally, hospitals should appoint infection control liaisons to offer guidance, monitor adherence and address concerns. Regular audits should be conducted to assess effectiveness and identify areas for improvement.	Assessment of infection transmission risks: Conduct research to assess the risks associated with multiple informal caregivers providing patient care, particularly in terms of infection transmission within hospitals, including occupational acquired infections. Explore strategies to mitigate these risks. Cultural impact on infection control: Investigate the cultural norms and expectations that influence informal caregiving in Vietnam. Understand how these factors shape infection control practices and identify opportunities to align infection control policies and practices with cultural values.
Recommendations relating to training informal caregivers		
Develop and implement formal training programmes for informal caregivers that are aligned with their specific needs and responsibilities. These culturally appropriate programmes should include components on infection control practices, patient care skills and	Provide practical, accessible training on basic infection prevention techniques, such as hand hygiene, waste disposal, PPE use, and patient handling practices. Where feasible, employ video demonstrations and visual aids that can be accessed repeatedly by caregivers, or implement a	Conduct longitudinal studies to assess the long-term impact of caregiver training programmes on patient outcomes and infection control practices. Measure the effectiveness of different training approaches.

communication with healthcare professionals.	peer-education model, using experienced informal caregivers as trainers. Delivery of training and education programmes: Healthcare facilities should establish regular training and education programmes for informal and commercial caregivers. These programmes should cover essential caregiving skills, infection control practices and the specific policies of the facility.	Effectiveness of support programmes: Evaluate the effectiveness of support programmes provided to informal caregivers within healthcare facilities. Assess the impact of these programmes on caregiver competence and patient outcomes.
Recommendations related to recognition of informal caregivers		
Recognition of commercial caregivers: Recognise and regulate the role of commercial caregivers within the healthcare system. Develop policies and guidelines that define their responsibilities, qualifications and the quality of care they must provide. Develop clear policies defining the roles, responsibilities, and infection control expectations for informal caregivers in hospital settings, including mandatory training requirements.		Comparative analysis of caregiver types: Conduct comparative research to assess the quality of care provided by family caregivers and commercial caregivers. Analyse patient outcomes and satisfaction levels to understand the strengths and weaknesses of each caregiving model.
Recommendations related to resource allocation for informal caregivers		

Implement national policies that formally recognize and regulate the role of informal caregivers in hospitals, facilitating structured support and integration within healthcare workflows. Develop policies that ensure informal caregivers have access to the necessary infection control supplies and training. Implement measures to prevent the misuse or removal of these supplies from healthcare facilities.	Allocate resources within healthcare facilities to support informal caregivers. This includes providing educational materials and access to training sessions, and ensuring the availability of infection control supplies.	Conduct a study to assess the effectiveness of resource allocation policies for informal caregivers in healthcare settings. Evaluate the impact of these policies on the accessibility of infection control supplies and training for informal caregivers. Measure outcomes such as caregiver satisfaction, adherence to infection control protocols and rates of healthcare-associated infections among patients receiving care from informal caregivers. Explore potential barriers to resource allocation implementation and identify strategies for optimising resource distribution to support informal caregivers effectively.
Recommendations related to informal caregiver interaction in the hospital environment		
Promote collaborative healthcare worker-caregiver relationships: Encourage healthcare facilities to establish clear guidelines and expectations for interactions between healthcare workers and informal caregivers. Promote collaboration and effective communication to enhance patient care outcomes.	Communication protocols: Establish clear communication protocols between healthcare workers and informal caregivers. Provide guidelines for sharing patient information and coordinating care.	Qualitative analysis of caregiver-healthcare worker interactions: Conduct qualitative research to explore the dynamics of interactions between healthcare workers and informal caregivers in depth. Understand the factors that contribute to conflicts and identify strategies for improving collaboration.

6.8 Conclusion

In conclusion, I have undertaken a comprehensive exploration of the role of informal caregivers in infection prevention and control within hospitals in low- and middle-income countries, with a specific focus on Vietnam. The aim and objectives set out to understand the practices, perceptions and experiences of informal caregivers, as well as healthcare workers' perspectives on their role in infection control. Through a systematic review of the literature and a focused ethnographic study, my research has provided valuable insights into the complexities of informal caregiving practices and their implications for infection control.

The findings of my study reveal the multifaceted nature of informal caregiver roles, encompassing a wide range of patient care practices and infection control behaviours. Informal caregivers play a crucial role in supporting patient care activities in hospitals, often undertaking tasks that directly impact infection control outcomes. Their perceptions of their role in infection prevention and control are influenced by various factors, including cultural norms, organisational dynamics and the availability of resources and support.

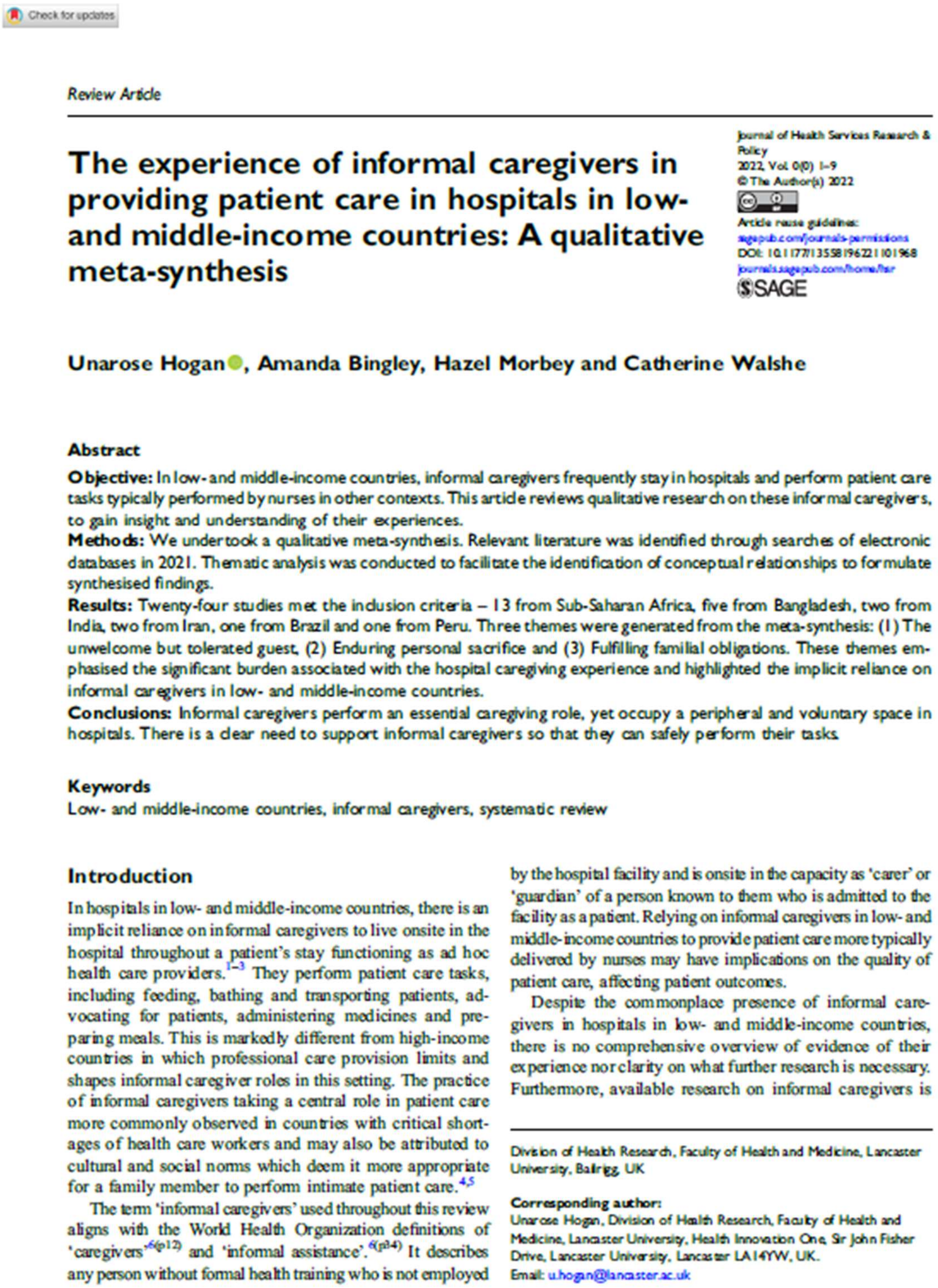
Furthermore, my research highlights the importance of understanding and addressing the challenges faced by informal caregivers in adhering to infection control practices. These challenges include limited access to training and guidance, inadequate resources and cultural barriers that affect their ability to implement recommended measures effectively. Healthcare workers' perceptions of informal caregivers' roles also influence their collaboration and support for infection control efforts, underscoring the need for effective communication and collaboration between formal and informal care providers.

In conclusion, my thesis contributes to the existing body of knowledge by providing a deeper understanding of the role informal caregivers play in infection prevention and control. The findings have implications for policy and practice, supporting tailored interventions to empower informal caregivers in their infection control roles. By addressing the identified challenges and promoting collaboration between healthcare workers and informal caregivers, healthcare systems can enhance patient safety and mitigate the risk of healthcare-associated infections in low- and middle-income countries. Finally, while my research has provided valuable insights, it is essential to acknowledge its limitations and the need for further research to build upon these findings and continue to advance our understanding of this important area.

7 7. Appendices

7.1 Appendix 1: Systematic review publication

Hogan, U. et al. (2022) ‘The experience of informal caregivers in providing patient care in hospitals in low- and middle-income countries: A qualitative meta-synthesis’, *Journal of Health Services Research & Policy*. doi: 10.1177/13558196221101968.



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The experience of informal caregivers in providing patient care in hospitals in low- and middle-income countries: A qualitative meta-synthesis

Unarose Hogan, Amanda Bingley, Hazel Morbey and Catherine Walshe

Abstract

Objective: In low- and middle-income countries, informal caregivers frequently stay in hospitals and perform patient care tasks typically performed by nurses in other contexts. This article reviews qualitative research on these informal caregivers, to gain insight and understanding of their experiences.

Methods: We undertook a qualitative meta-synthesis. Relevant literature was identified through searches of electronic databases in 2021. Thematic analysis was conducted to facilitate the identification of conceptual relationships to formulate synthesised findings.

Results: Twenty-four studies met the inclusion criteria – 13 from Sub-Saharan Africa, five from Bangladesh, two from India, two from Iran, one from Brazil and one from Peru. Three themes were generated from the meta-synthesis: (1) The unwelcome but tolerated guest, (2) Enduring personal sacrifice and (3) Fulfilling familial obligations. These themes emphasised the significant burden associated with the hospital caregiving experience and highlighted the implicit reliance on informal caregivers in low- and middle-income countries.

Conclusions: Informal caregivers perform an essential caregiving role, yet occupy a peripheral and voluntary space in hospitals. There is a clear need to support informal caregivers so that they can safely perform their tasks.

Keywords

Low- and middle-income countries, informal caregivers, systematic review

Introduction

In hospitals in low- and middle-income countries, there is an implicit reliance on informal caregivers to live onsite in the hospital throughout a patient's stay functioning as ad hoc health care providers.[1–3] They perform patient care tasks, including feeding, bathing and transporting patients, advocating for patients, administering medicines and preparing meals. This is markedly different from high-income countries in which professional care provision limits and shapes informal caregiver roles in this setting. The practice of informal caregivers taking a central role in patient care more commonly observed in countries with critical shortages of health care workers and may also be attributed to cultural and social norms which deem it more appropriate for a family member to perform intimate patient care.[4,5]

The term 'informal caregivers' used throughout this review aligns with the World Health Organization definitions of 'caregivers'[6(p12)] and 'informal assistance'.[6(p34)] It describes any person without formal health training who is not employed by the hospital facility and is onsite in the capacity as 'carer' or 'guardian' of a person known to them who is admitted to the facility as a patient. Relying on informal caregivers in low- and middle-income countries to provide patient care more typically delivered by nurses may have implications on the quality of patient care, affecting patient outcomes.

Despite the commonplace presence of informal caregivers in hospitals in low- and middle-income countries, there is no comprehensive overview of evidence of their experience nor clarity on what further research is necessary. Furthermore, available research on informal caregivers is

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primarily drawn from the quality of life and burden of caregiving surveys or focused on caregiving in the community for chronic diseases and does not distinguish between high-income and low/middle-income countries.[7,8] The focus of this meta-synthesis was to review qualitative research investigating informal caregivers' experience of providing patient care in hospitals in low- and middle-income countries to gain insight and understanding of their perspectives.[9] The specific review question is: 'How do informal caregivers experience their role in providing patient care in hospitals in low- and middle-income countries?'

Methods

We undertook a qualitative meta-synthesis, following the six steps formulated by Sandelowski and Barroso.[10] This facilitates interrogation of findings from different studies to produce new interpretations of the data resulting in a more holistic understanding of the experience. This approach is well suited to exploring individual experiences rooted in a constructivist epistemology.[11,12] The practical value of systematic qualitative synthesis lies in the collation of qualitative material for other researchers who would not have the capacity to locate, read and interpret all the material individually. The protocol for this systematic review is available on PROSPERO (https://www.crd.york.ac.uk/prospero/), number CRD42017082345.

Step 1: Formulating a review question

A SPIDER model approach was used, covering:[13]

- Sample: informal caregivers in hospitals in low- and middle-income countries
- Phenomenon of Interest: experience perspective, attitudes, views, beliefs and perspectives of informal caregivers engaged in care provision in hospitals in low- and middle-income countries.
- Design: ethnography, phenomenology, grounded theory, all qualitative variations, interviews and observation
- Evaluation: the experience of caregiving
- Research Type: qualitative

Step 2: Comprehensive systematic search

We obtained studies on the experiences of informal caregivers in hospitals in low- and middle-income countries. Four categories of search terms were used: 'informal caregivers', 'hospitals in low- and middle-income countries list', 'patient care' and 'personal experience'. Relevant literature was identified by searching the electronic databases MEDLINE, Embase, CINAHL, PubMed and PsycINFO between 5 June and 20 July 2021 inclusive (see online supplement 1).

The process involved iterative searches and hand searching, backward and forward citation searching and berry picking (a non-linear circuitous search process).[14] Search results were read for relevance and applied to the inclusion and exclusion criteria for review, outlined in online supplement 1. Initial exclusion was performed by the primary author (UH) with consensus on the final list of articles to be examined derived from a discussion with two researchers (AB and CW). This process is depicted in online supplement 1.

Step 3: Study selection and appraisal

Studies meeting the inclusion criteria were appraised using the Critical Appraisal Skills Programme, which is widely used to demonstrate rigour in the quality appraisal of evidence to be synthesised.[12] The purpose of this assessment was to ensure the accurate identification of the explicit elements of quality in qualitative research, avoid drawing unreliable conclusions and consider the degree of reflexivity of the researcher as a hallmark for quality.[9,15] The appraisal was not intended to be a tool for exclusion of studies. That is because research participants' perspectives can be accurately represented even in low-quality studies, and research findings may still be relevant.[16]

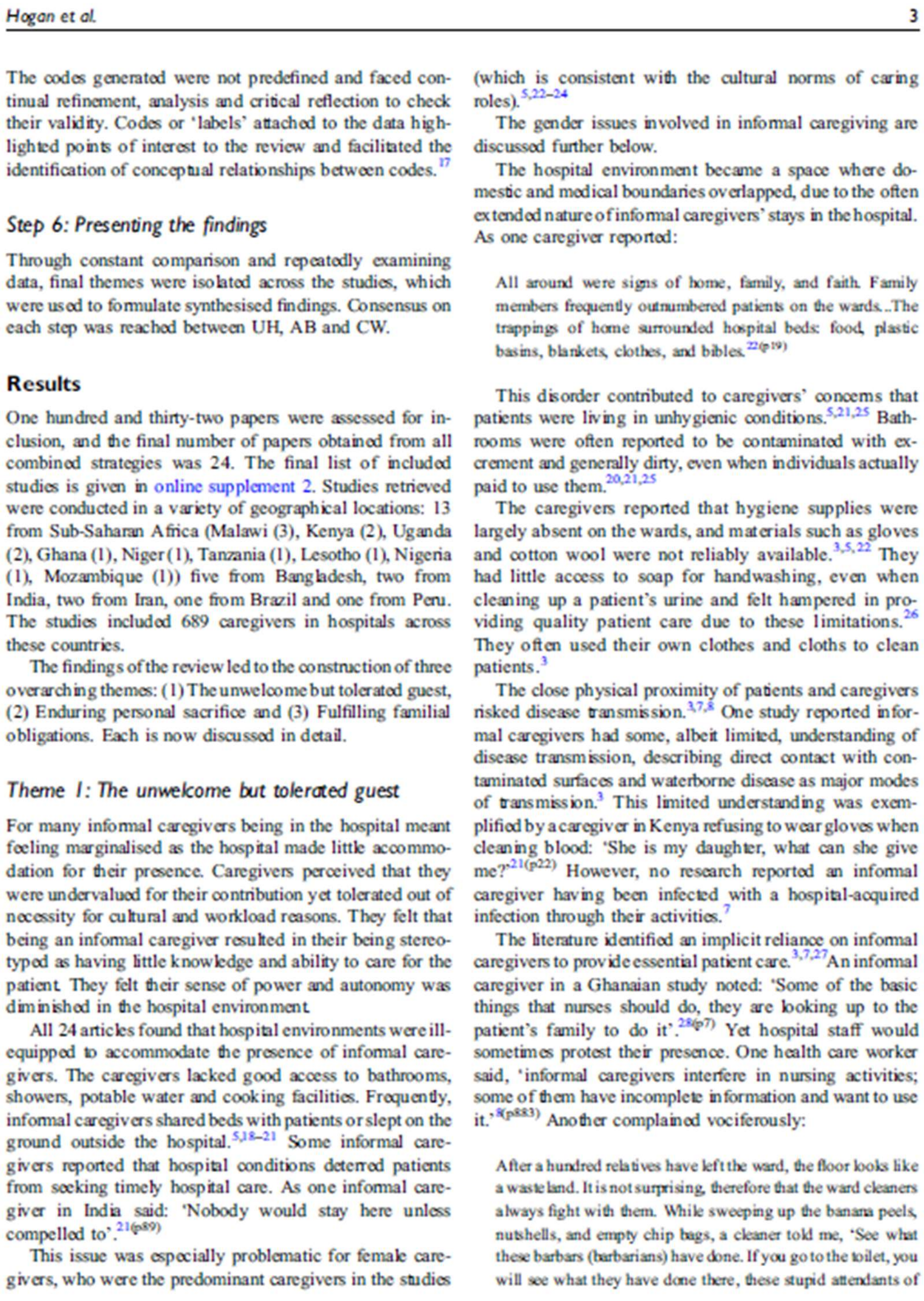
Step 4: Analysing and synthesising findings

A thematic approach was used to synthesise the qualitative studies. Thematic analysis is a means of analysing and reporting patterns identified within and across data sets. It is flexible in process and can provide insight into the experience of individual and factors influencing their actions.[16]

Step 5: Quality Control of synthesis output

For consistent data to be extracted for this systematic review, a qualitative data extraction tool was adapted from an existing National Institute of Clinical Excellence tool. The domains of study setting, objectives, design, data collection and analysis, methods and themes were extracted from the primary research articles. Given the exploratory nature of this systematic review, 'findings' were understood to be 'key concepts' arising from the research findings and other relevant details derived from various parts of the publication.[16] Relevant information included all data related to informal caregivers' experience, perspective, attitudes, views, beliefs and practices regarding patient care provision in hospitals.

Using NVivo software, data were coded (UH) and organised hierarchically into 'coding trees' according to emergent concepts and their relationship to one another.



The codes generated were not predefined and faced continual refinement, analysis and critical reflection to check their validity. Codes or 'labels' attached to the data highlighted points of interest to the review and facilitated the identification of conceptual relationships between codes.[17]

Step 6: Presenting the findings

Through constant comparison and repeatedly examining data, final themes were isolated across the studies, which were used to formulate synthesised findings. Consensus on each step was reached between UH, AB and CW.

Results

One hundred and thirty-two papers were assessed for inclusion, and the final number of papers obtained from all combined strategies was 24. The final list of included studies is given in online supplement 2. Studies retrieved were conducted in a variety of geographical locations: 13 from Sub-Saharan Africa (Malawi (3), Kenya (2), Uganda (2), Ghana (1), Niger (1), Tanzania (1), Lesotho (1), Nigeria (1), Mozambique (1)) five from Bangladesh, two from India, two from Iran, one from Brazil and one from Peru. The studies included 689 caregivers in hospitals across these countries.

The findings of the review led to the construction of three overarching themes: (1) The unwelcome but tolerated guest, (2) Enduring personal sacrifice and (3) Fulfilling familial obligations. Each is now discussed in detail.

Theme 1: The unwelcome but tolerated guest

For many informal caregivers being in the hospital meant feeling marginalised as the hospital made little accommodation for their presence. Caregivers perceived that they were undervalued for their contribution yet tolerated out of necessity for cultural and workload reasons. They felt that being an informal caregiver resulted in their being stereotyped as having little knowledge and ability to care for the patient. They felt their sense of power and autonomy was diminished in the hospital environment.

All 24 articles found that hospital environments were ill-equipped to accommodate the presence of informal caregivers. The caregivers lacked good access to bathrooms, showers, potable water and cooking facilities. Frequently, informal caregivers shared beds with patients or slept on the ground outside the hospital.[5,18–21] Some informal caregivers reported that hospital conditions deterred patients from seeking timely hospital care. As one informal caregiver in India said: 'Nobody would stay here unless compelled to'.[21(p89)]

This issue was especially problematic for female caregivers, who were the predominant caregivers in the studies (which is consistent with the cultural norms of caring roles).[5,22–24]

The gender issues involved in informal caregiving are discussed further below.

The hospital environment became a space where domestic and medical boundaries overlapped, due to the often extended nature of informal caregivers' stays in the hospital. As one caregiver reported:

> All around were signs of home, family, and faith. Family members frequently outnumbered patients on the wards...The trappings of home surrounded hospital beds: food, plastic basins, blankets, clothes, and bibles.[22(p19)]

This disorder contributed to caregivers' concerns that patients were living in unhygienic conditions.[5,21,25] Bathrooms were often reported to be contaminated with excrement and generally dirty, even when individuals actually paid to use them.[20,21,25]

The caregivers reported that hygiene supplies were largely absent on the wards, and materials such as gloves and cotton wool were not reliably available.[3,5,22] They had little access to soap for handwashing, even when cleaning up a patient's urine and felt hampered in providing quality patient care due to these limitations.[26] They often used their own clothes and cloths to clean patients.[3]

The close physical proximity of patients and caregivers risked disease transmission.[3,7,8] One study reported informal caregivers had some, albeit limited, understanding of disease transmission, describing direct contact with contaminated surfaces and waterborne disease as major modes of transmission.[3] This limited understanding was exemplified by a caregiver in Kenya refusing to wear gloves when cleaning blood: 'She is my daughter, what can she give me?'[21(p22)] However, no research reported an informal caregiver having been infected with a hospital-acquired infection through their activities.[7]

The literature identified an implicit reliance on informal caregivers to provide essential patient care.[3,7,27] An informal caregiver in a Ghanaian study noted: 'Some of the basic things that nurses should do, they are looking up to the patient's family to do it'.[28(p7)] Yet hospital staff would sometimes protest their presence. One health care worker said, 'informal caregivers interfere in nursing activities; some of them have incomplete information and want to use it.'[8(p883)] Another complained vociferously:

> After a hundred relatives have left the ward, the floor looks like a wasteland. It is not surprising, therefore that the ward cleaners always fight with them. While sweeping up the banana peels, nutshells, and empty chip bags, a cleaner told me, 'See what these barbars (barbarians) have done. If you go to the toilet, you will see what they have done there, these stupid attendants of

> the patients come from the village and do not know how to use a toilet.'[29(p283)]

Personal and intimate care of patients was viewed in some social contexts as degrading to nurses.[4] In some Islamic cultures, physical contact between females and non-family members is prohibited, which interfered with health care workers' willingness to engage in patient interaction.[3,4] Implied here is a reliance on informal caregivers to undertake nurse functions that would otherwise go unperformed due to cultural norms. In Bangladesh, for instance, nurses working night duty carry a cultural stigma of being associated with nighttime commercial sex work, which reduces nurses' 'bride market' value.[3] To reduce the stigma associated with the nursing profession, nurses distance themselves from patients, and patients' relatives become nurse surrogates.[4,7] One informal caregiver said:

> I think nurses feel they are superior to poor patients and their carers. They don't like to associate with us because we are poor and dirty. They maintain a distance from these jobs in case their white dress might become dirty.[4(p1171)]

Informal caregivers who felt obliged to perform personal care tasks reported a similar culturally rooted sense of stigma and shame in their role. One caregiver in Nigeria explained that some villagers may become violent given what the caregiver is doing for the caregiver's mother:

> In my culture, children are forbidden from seeing the nakedness of their parents. I am sad when I see her exposed body every day. I always remember that it is unacceptable in our culture to see a parent's nakedness. But if I do not provide care for her, who else will? I am afraid for my life because of the repercussions of the taboo on me.[30(p2629)]

The burden of caregiving extended to marital and familial relationships, placing strain on these, with several studies reporting worry and fear about the wellbeing of family at home.[2,24,31,32]

As one caregiver reported, 'Sometimes it brings the morale of the family down, especially with the children.'[31(p321)]

In several studies, informal caregivers perceived health care workers as strict, uncaring and unwilling to do routine patient care. The caregivers rationalised their role as de facto nurses, performing functions nurses were unwilling to do.[3,4] As one caregiver reported:

> They [nurses] think as an educated person these tasks should not be their work, nor should they serve or give personal care to uneducated or poorly educated people.[4(p1171)]

Informal caregivers were frustrated as they felt health care workers did not recognise their contribution to patient care.[18,23,31] The caregivers expressed a desire for a family-centred approach to care, where they would be active participants in decisions, but felt unable to raise this with health workers, who often stereotyped them as incompetent.[24] Some informal caregivers felt reluctant to ask the nurses and doctors questions because they were afraid it would result in a reprimand. As noted in one Malawian study:

> It is difficult for us to explain the patient's problem to the nurses; for example, you can tell the nurse the patient's problem, and she will answer, 'you do not listen! Wait for the doctor and tell him', this discourages us to ask anything.[20(p808)]

This fear of reprimand was echoed in other studies where informal caregivers had concerns over patient care, such as worrying that drawing blood frequently would weaken their child, especially when they did not understand why it was necessary.[24,29]

In general, informal caregivers were more likely to criticise nurses', rather than doctors', attitudes towards them. This may be indicative of the fact caregivers interact with nurses with more frequently and that doctors have a higher perceived status. The sense of disempowerment felt by informal caregivers and their subservience to the authority of health workers within the hospital environment featured prominently.[24,27,33] Informal caregivers frequently expressed a desire to feel less marginalised. As one daughter reported:

> I just sit here like a robot. Nurses asked me to buy items that my mother needed. They never told me why she needed them. They ordered me to pay for dialysis, laboratory investigations and other things. I don't like it when I do not know the reason behind my actions. I am sad to see myself as a fool being tossed around.[30(p2627)]

Informal caregivers felt they added value to patient care, but that this was unrecognised by health workers, who saw them as poor and uneducated.[7,31]

Theme 2: Enduring personal sacrifice

For many informal caregivers being in the hospital imposed significant personal sacrifice. Their caregiving role in the hospital negatively impacted their physical, emotional and social wellbeing. The impact of the caregiving experience was not confined within the hospital boundaries; rather, relationships and job prospects outside the hospital also suffered. The caregiving role also carried the burden of various costs.

Informal caregivers experienced physical injuries associated with caregiving, including hip pain and back

problems from lifting patients.[34] They faced barriers in accessing nutrition and caring for their personal health when in the hospital.[21] Caregivers described day-to-day care as exhausting and stressful. They frequently experienced fatigue and insomnia, which was particularly pronounced among older caregivers.[18,31,35,36] Integral to the caregivers' emotions was the physical state of the patient they were looking after, the patient's deteriorating health and fear of death.[28,37,38]

Prolonged periods of caregiving saw some caregivers experience depressive symptoms such as tiredness, sadness, difficulty sleeping, lack of motivation and suicidal ideation.[30,34,36] Informal caregivers worried that they exacerbated the patient's discomfort, confirmed by a patient's body language or complaints.[37,38] For instance, caregivers caring for HIV and AIDS patients felt discomfort and repulsion when dealing with the patients' bodily fluids, and feared the patients would misinterpret this as an unwillingness to help.[37] They also were stressed by the uncertainty over a patient's condition, the patient's physical condition and unknown HIV status.[37] One caregiver said:

> I was using those Dettols [disinfectants], but I am worried that I could be having it [HIV] already. Maybe he has infected me. I am worried that I have it because I did not protect myself when I was touching all that stuff and bathing him…no one gave me the gloves, not even the nurse at the hospital.[37(p23)]

The death of a loved one were traumatic for some informal caregivers and contributed to their emotional burden.[23,36]

Caregivers described how caregiving had imposed restrictions on their lives and prevented them from engaging in social activities.[30] Stressors included a lack of independence and time to engage in social activities due to their having to be at the hospital.[34] Social isolation included loneliness, conflicts with other family members regarding decisions, lack of support from the broader family, being unable to undertake other regular social activities (such as playing with their children) and having to put their social life on hold.[23,24,31,34]

Often mentioned was the impact on the informal caregiver's ability to earn a livelihood. Most caregivers stopped working altogether in order to care for their family members. As one explained:

> I abandoned my search for [a] job because I have to provide care. I felt that my future plan has been jeopardised since it is impossible for me to apply for a job from the hospital environment. My colleagues are employed and making future plans while I am here providing care.[30(p2627)]

Informal caregivers faced difficulties in balancing their professional, family and caregiving roles, as they were unable to be physically present in all places.[21,31,32] Several mothers reported concerns of being unavailable to care for other children at home while others brought young infants to the hospital to remain with them.[21,31,32] Some informal caregivers began looking after the children of the sick patient, extending their role beyond the hospital. One Ugandan caregiver providing care for her widowed HIV-positive sister reported she cared for 20 children at home, including her sister's children.[31] Caregiving had impacts on marital relationships, with several studies reporting worry and fear about the wellbeing of spouses at home.[21,31,32]

Informal caregivers bore significant financial burdens due to caregiving.[23] Being unable to work, many were wholly dependent on the financial support of other family members (who sometimes failed to do so consistently). Caregivers assumed responsibility for the expenses associated with care, including the cost of drugs, food, transport to the hospital and other associated costs. Informal caregivers mostly relied on collective financial support from family networks to meet these costs.[18,20,31,34] In Nigeria, one informal caregiver noted:

> I sleep outside on the veranda within the hospital with other family caregivers…I couldn't afford the hostel fee; if I pay the hostel fee, it may affect our ability to buy drugs, so I sleep outside.[28(p6)]

Theme 3: Fulfilling familial obligations

For many informal caregivers being in the hospital meant they were fulfilling what they regarded as an inevitable role and duty. In some cases, this made it easier for caregivers to adapt to the caregiving role. It also fostered closer relationships and empathy for their patients. But in other cases, it brought an additional strain to the relationship.

Most studies identified familial obligation as the reason a caregiver took on the caregiving role.[30,36] A healthy caregiver–patient relationships strengthened the informal caregiver's ability to fulfil their role.[31,36] Time the caregiver spent with the patient promoted a closer relationship between them, particularly when caregiving was prolonged.[30] There was a sense of pride among informal caregivers at being able to perform a caregiving role for their family member, strengthening the relationship. As a wife caring for her husband commented:

> I feel fulfilled that I am able to provide care to my husband…of 30 years…The type of care I provide for him makes him happy, and it has strengthened our love for each other.[30(p2629)]

Caregivers empathised with their patients, notably when the patient was in pain. Empathy was particularly pronounced in a maternal-child relationship. As one 71-year-old woman caring for her son said: 'I'd rather die just to save him.'[31(p321)]

When patients were resistant to receiving care, the informal caregiver-patient relationship suffered. Informal caregivers described some patients as 'difficult',[34(p36)] 'demanding'[34(p36)] and 'bad-tempered'[34(p36)] and noted they refused medication or personal care. Informal caregivers who experienced this felt anger, frustration and stressed.[37]

Women primarily fulfilled the caregiving role. Males typically only undertook caregiving when it would impractical for the women to do so (for instance, the women had to look after young children or were physically incapable of doing caregiving work).[22,29,32] But a Bangladeshi study found the male informal caregivers cared for male patients. This is because it would be inappropriate for women to stay in a male hospital ward as that would breach the practice of purdah (seclusion of females from males and strangers).[29]

In some cases, fulfilling this familial duty led caregivers to accept the role with a sense of positive wellbeing.[24,27,29,31] Informal caregivers were positively influenced by previous caregiving experience.[28] Gaining skills as a caregiver led to enhanced feelings of confidence, further increasing the ease with which they adapted to the role.[7,21] Closely linked to confidence were feelings of resilience brought about by the acquisition of new skills, as described by one informal caregiver in India:

> Baba (father) always took all major decisions, related to managing finances, property, major family decision. Now that he is not well, I am learning to manage those.[21(p83)]

Coping strategies which supported ease of adapting to the caregiving role included a positive attitude to the situation, achieved through good humour and avoiding seeing caretaking as an obligation.[28,36] One caregiver explained that sharing caregiving responsibilities helped her have a more autonomous life, reducing the emotional burden of caregiving.[34] Informal caregivers used religion, spirituality, prayer and meditation as sources of strength and resilience to manage anger and anxiety.[31,34,39]

Informal caregivers came to rely on other informal caregivers as a source of support. They developed a social bond at the hospital and took responsibility to notify each other in case of an emergency, ensuring that the absent caregiver had time for rest.[21] According to one Bangladeshi informal caregiver:

> We (family caregivers) stay here (in-patient ward) like a family. If one family caregiver has to go to call the nurse and leaves their patient alone, I stay near that patient and keep an eye on him or her.[3(p308)]

Discussion

Our findings provide a consistent account of the distinctive experience of informal caregivers providing care to family members in hospitals in low- and middle-income countries.

The first theme, the unwelcome but tolerated guest, highlights the fact that informal caregivers are an essential, albeit frequently unrecognised, group of care providers in hospitals in low- and middle-income countries. Underpinning this is the lack of power the informal caregiver has in the hospital context, with little influence over decision-making in patient care.[40]

There are considerable advantages in involving family members in patient care, and these are associated with a range of positive outcomes, including reducing the stress of providing such care, improving patient empowerment and improving relationships with health care workers.[41] But informal caregivers perceived health care workers as apathetic towards their caregiving contributions. Hospitals should support and upskill informal caregivers. The unskilled provision of patient care is consistently associated with poorer patient outcomes, and the need for improved health literacy is most acute in low- and middle-income countries.[42]

Adding informal caregivers to patients' care team may open up access to better resources, protections and education for the health system.[35,43] Legislation has been suggested in Cambodia to cover how nurses should supervise unqualified service providers.[44] Similar laws could be considered elsewhere.

The second theme, enduring personal sacrifice, emphasises the stressful burden of undertaking informal caregiving.[41,45] This is consistent with the theoretical framework of the Stress Process Model, which identifies caregiver stress as a complex response to internal and external demands affecting psychological, relational and social resources interactions.[36] While the burden of caregiving is a universal experience, its effects may be most acutely felt when considered against in a context of poverty and other pre-existing stressors. The need to develop and integrate psychosocial interventions – such as peer support, and stigma- and anxiety-reduction programmes – is vital to support caregivers to continue their role.[45]

The direct and indirect financial costs associated with caregiving are likely to have a more pronounced impact in low- and middle-income countries.[7,31] Moreover, continued future reliance on the informal caregiver group to provide patient care cannot be assured in modern contexts where urban migration for employment and women working outside the home may reduce the future availability of informal caregivers.[31,45,46] Financial support for informal caregivers – including to cover accommodation, meals and transport – could be considered.[41]

The third theme, fulfilling familial obligations, reflects the sense of duty among caregivers and their ability to adapt to their role. Indeed, caregivers can find the role rewarding and life enhancing.[23,30] Caregivers seek out family support, forge alliances with other caregivers and use spiritual practices as strategies to cope with the role.[31,47] To maintain a good quality relationship between the caregiver and patient, support programmes have been effective in reducing caregiver distress and fostering higher self-esteem among caregivers.[49]

Informal caregivers are frequently women. This potentially exacerbates an enduring gender inequality in low- and middle-income countries by perpetuating a system that prevents women entering paid employment and, instead, leaves them in poverty.[48] Gendered relations of caregiving need to be addressed in policies and practices for caregiving to reduce the impact on women and account for the responsibilities of traditional roles of women in many of the countries.[48]

One gap in the literature is the lack of research into informal caregivers' potential exposure to disease. The occupational risk of disease transmission among health care workers is well established, but a similar risk may exist among informal caregivers who perform patient care.[49] The patient care practices caregivers perform, their exposure to the hospital environment and lack of access to infection prevention and control infrastructure, as well as their limited understanding of disease transmission and preventative practices, may leave caregivers exposed to greater risk of infection. No study in this review reported whether an informal caregiver was exposed to or transmitted an infectious agent while in a hospital. Indeed, low- and middle-income countries frequently lack the necessary laboratory support and hospital-acquired infection surveillance systems necessary for hospital-associated infection reporting.[49] Several studies elsewhere have acknowledged the role of family members as contributors to hospital transmission of disease.[50] In today's context of the COVID-19 pandemic and emerging pathogens, adherence to best infection prevention and control principles by all people in hospitals is essential. This must include informal caregivers.

This review did not explore the perception of health care workers towards informal caregivers, how that may influence the development of a better therapeutic relationship to support the patient and how willing health care workers would be to being informal caregiver educators. This is an area for further research to inform appropriate educational and supportive interventions.

Limitations

There are four main limitations to this study. First, although the included studies had a broad geographical range, many countries where informal caregivers are typical were underrepresented or did not appear at all.

Second, our study was obliged to focus on interview-based research rather than observation. That is because the majority of the included studies used in-depth interviews or focus groups as their data collection method. Only eight studies adopted observation as a component of their data collection.[3,18,21,22,26,27,29,33] There can be differences between what interviewees self-report and what an independent researcher observes. This indicates a need for additional observational qualitative research to further understand the experience of the informal caregiver.

Third, the rigorous Critical Appraisal Skills Programme tool used for analysing the included studies can only assess the reporting of these studies, rather than how they were conducted. Our study therefore required a subjective judgement that the studies did accurately reflect the perspectives of the research participants.[12]

Fourth, our study did not include any research on caregiver restrictions that may have been imposed due to the COVID-19 pandemic. The importance of the informal caregiver role as a potential bridging population between the hospital and the community in view of COVID-19 and other forms of infection warrants further research.

Conclusions

Informal caregivers perform an essential caregiving role in hospitals in low- and middle-income countries but occupy a peripheral and voluntary space in the hospitals. In countries where a critical shortage of health care workers and a cultural reliance on informal caregivers persists, continuing to devalue them within the health system may be detrimental to patient outcomes and negatively affect the broader population health and health system. There is a clear need to support informal caregivers so that they can perform their role safely.

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Supplemental Material

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7.2 Appendix 2: Systematic review PROSPERO protocol

PROSPERO
International prospective register of systematic reviews

NHS
National Institute for
Health Research

What are informal caregivers roles and experiences in patient care provision in hospital in low and middle-income countries?

Unarose Hogan, Catherine Walsh, Amanda Bingley

Citation

Unarose Hogan, Catherine Walsh, Amanda Bingley. What are informal caregivers roles and experiences in patient care provision in hospital in low and middle-income countries? . PROSPERO 2017 CRD42017082345 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017082345

Review question

1. What roles do informal caregivers fulfil in the provision of patient care in hospitals in low and middle-income countries?
2. How do informal caregivers experience their role in the provision of patient care in hospitals in low and middle-income countries?

Searches

Scoping search: Cochrane, PROSPERO, MEDLINE

Comprehensive Search: MEDLINE, CINAHL, PROSPERO, PsycINFO will be searched for studies published in English for relevance and applied to the inclusion and exclusion criteria for the review. The search terms will exclude methodological filters for qualitative research to improve sensitivity. Additional hand searching and citation snowballing techniques will be used.

There will be no time restrictions on the search.

Types of study to be included

We will include primary qualitative studies of all methodologies including ethnographic, grounded theory, phenomenological, participatory action research using inquiry methods such as interview, focus groups and ethnographic observations.

Qualitative systematic reviews and mixed method studies which report on qualitative findings will also be eligible for inclusion.

Condition or domain being studied

Patient care in hospitals in low and middle income countries.

Participants/population

Inclusion: Informal caregivers providing patient care in hospitals in low and middle-income countries

Exclusion: Studies focused on health care workers providing patient care in hospitals in low and middle-income countries

Intervention(s), exposure(s)

Focus is on patient care provision practices in hospitals in low and middle-income countries

Comparator(s)/control

Not applicable

Primary outcome(s)

Relevant outcomes will include experience, perspective, attitudes, views, beliefs, practices, barriers to and opportunities for patient care provision among informal caregivers in hospitals in low and middle income countries.

Secondary outcome(s)

None

Data extraction (selection and coding)

Titles and abstracts of studies retrieved using the search strategy and those from additional sources will be screened independently by two review authors to identify studies that potentially meet the inclusion criteria outlined above. The full text of these potentially eligible studies will be retrieved and independently assessed for eligibility by two review team members. Any disagreement between them over the eligibility of particular studies will be resolved through discussion with a third reviewer. A data extraction tool adapted from the National Institute Clinical Excellence (NICE, 2007) will be applied for consistent data extraction. Extracted information will include: study aim, design, conceptual model of theory used, key findings, start and end dates, ethical approvals obtained, sample, inclusion and exclusion criteria, selection rationale, sample size, setting, method of participant recruitment, informed consent obtained, data collection methods, role of the researcher, fieldwork conducted, data analysis methods, researcher bias identified, reflexivity, themes generated and key conclusions, implications for policy and practice, implications for further research and study limitations. Two review authors will extract data independently, discrepancies will be identified and resolved through discussion (with a third author where necessary). Missing data will be requested from study authors.

Risk of bias (quality) assessment

The Critical Appraisal Skills Programme (CASP) checklist for qualitative research will be adapted and used to assess quality in this review and applied to articles found on the basis of the search criteria. This checklist will assess the research aim, methodology, design, theory used, recruitment procedures, data collection methods, researcher role, ethics approvals obtained, rigour and research quality. Two review authors will apply the CASP checklist to the articles and any disagreement between them over the quality of particular studies will be resolved through discussion with a third reviewer.

Strategy for data synthesis

We will provide a narrative account of the findings from the included studies, structured around the themes emerging from the data in relation to the review question.

Analysis of subgroups or subsets

It is not possible to identify the subgroups in advance of performing the analysis.

Contact details for further information

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Organisational affiliation of the review

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Anticipated or actual start date

01 February 2017

Anticipated completion date

30 April 2018

Funding sources/sponsors

None

Conflicts of interest

Language

English

Country

Vietnam, England

Stage of review

Review_Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Caregivers; Home Nursing; Hospitals; Humans; Income

Date of registration in PROSPERO

27 November 2017

Date of publication of this version

12 December 2017

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	Yes	No
Risk of bias (quality) assessment	Yes	No
Data analysis	No	No

Versions

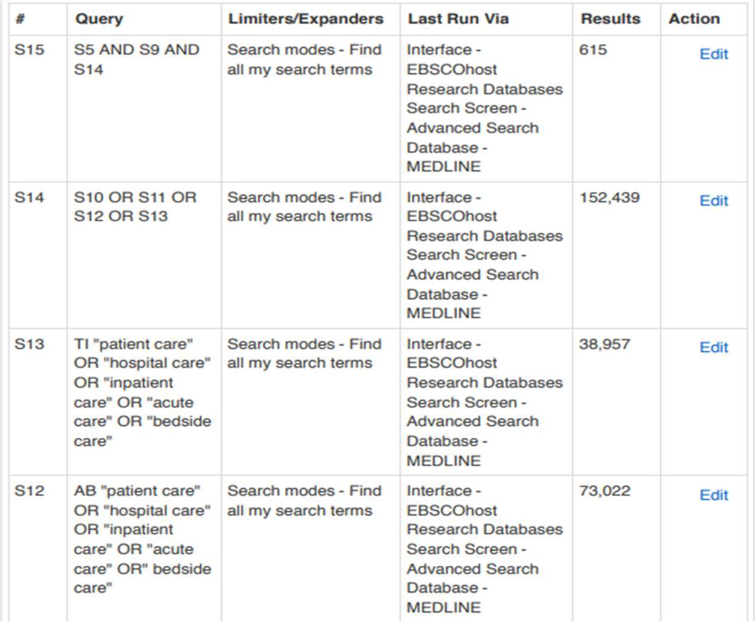
27 November 2017
12 December 2017

7.3 Appendix 3: Detailed list of search terms

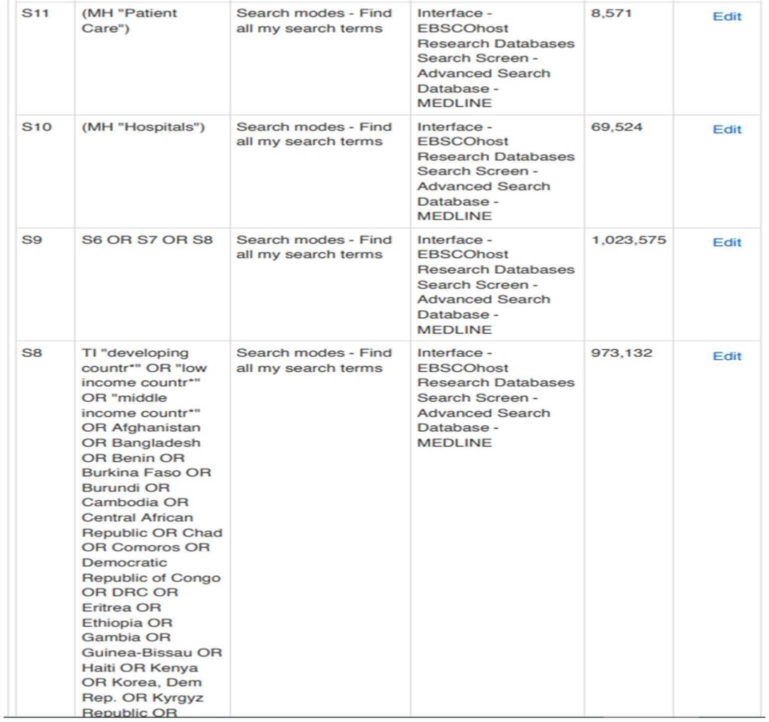
Category	MeSH heading	Variations
Population terms	MeSH heading (MH "Caregivers")	VARIATIONS for title and abstract search TI “caregivers OR "family caregiver*" OR guardian* OR "patient guardian*" OR "Informal caregivers" AB caregivers OR "family caregiver*" OR guardian* OR "patient guardian*" OR "Informal caregivers
Setting terms	MeSH: MH "Developing Countries")	VARIATIONS for title and abstract search TI "developing countr*" OR "low income countr*" OR "middle-income countr*" AB "developing countr*" OR "low income countr*" OR "middle-income countr*" AB "developing countr*" OR "low income countr*" OR "middle-income countr*"
	WB list LIC and Low middle-income countries	Afghanistan OR Bangladesh OR Benin OR Burkina Faso OR Burundi OR Cambodia OR Central African Republic OR Chad OR Comoros OR Democratic Republic of Congo OR DRC OR Eritrea OR Ethiopia OR Gambia OR Guinea-Bissau OR Haiti OR Kenya OR Korea, Dem Rep. OR Kyrgyz Republic OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mozambique OR Myanmar OR Nepal OR Niger OR Rwanda OR Sierra Leone OR Somalia OR Tajikistan OR Tanzania OR Togo OR Uganda OR Zimbabwe OR Albania OR Armenia OR Belize OR Bhutan OR Bolivia OR Cameroon OR Congo, Rep. OR Côte d'Ivoire OR Djibouti OR Egypt OR El Salvador OR Fiji OR Georgia OR Ghana OR Guatemala OR Guyana OR Honduras OR Indonesia OR India OR Iraq OR Kiribati OR Kosovo OR Lao PDR OR Lesotho OR Marshall Islands OR Micronesia OR Moldova OR Mongolia OR Morocco OR Nicaragua OR Nigeria OR Pakistan OR Papua New Guinea OR Paraguay OR Philippines OR Samoa OR São Tomé and Principe OR Senegal OR Solomon Islands OR South Sudan OR Sri Lanka OR Sudan OR Swaziland OR Syrian Arab Republic OR Syria OR Timor-Leste OR Tonga OR

		Ukraine OR Uzbekistan OR Vanuatu OR Vietnam OR West Bank and Gaza OR Yemen OR Zambia
	Hospitals/ health facility	INPATIENT- acute care
Health topic terms	Patient care	Bedside care acute care
Phenomena terms	Experience; Roles Practices	EXPIERENCE / VARIATIONS for title and abstract search AB experience* OR role* OR "patient care" OR activities OR practice* OR "hospital care" TI experience* OR role* OR "patient care" OR activities OR practice* OR "hospital care"
	Role	TI experience* OR role* OR "patient care" OR activities OR practice* OR "hospital care" VARIATIONS for title and abstract search + adverse events – hospital infection and so on + tasks they perform under patient care
Qual. research filters	None	Methodological filters for qualitative research have been developed but have undergone little replication and validation so were excluded in the search to improve sensitivity and excluded manually based on methodology (Tong et al., 2012, Carroll et al., 2011).
Search Limits	English language	

7.4 Appendix 4: Detailed Medline database search strategy



#	Query	Limiters/Expanders	Last Run Via	Results	Action
S15	S5 AND S9 AND S14	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	615	Edit
S14	S10 OR S11 OR S12 OR S13	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	152,439	Edit
S13	TI "patient care" OR "hospital care" OR "inpatient care" OR "acute care" OR "bedside care"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	38,957	Edit
S12	AB "patient care" OR "hospital care" OR "inpatient care" OR "acute care" OR" bedside care"	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	73,022	Edit

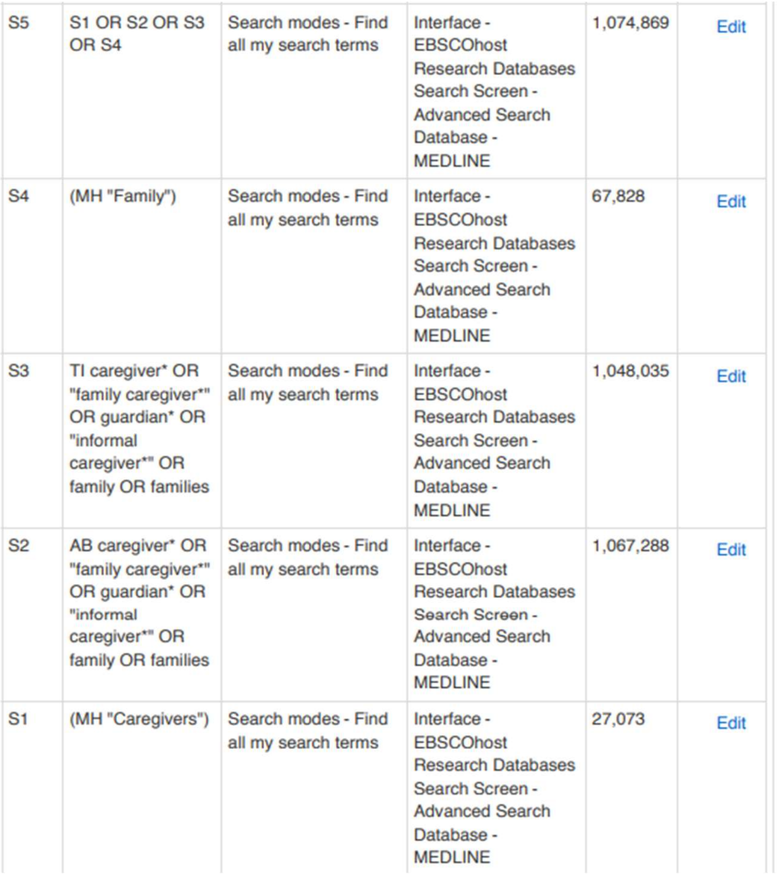


S11	(MH "Patient Care")	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	8,571	Edit
S10	(MH "Hospitals")	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	69,524	Edit
S9	S6 OR S7 OR S8	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,023,575	Edit
S8	TI "developing countr*" OR "low income countr*" OR "middle income countr*" OR Afghanistan OR Bangladesh OR Benin OR Burkina Faso OR Burundi OR Cambodia OR Central African Republic OR Chad OR Comoros OR Democratic Republic of Congo OR DRC OR Eritrea OR Ethiopia OR Gambia OR Guinea-Bissau OR Haiti OR Kenya OR Korea, Dem Rep. OR Kyrgyz Republic OR	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	973,132	Edit

6/3/2017 Create or Edit Saved Searches: EBSCOhost

Mozambique OR Myanmar OR Nepal OR Niger OR Rwanda OR Sierra Leone OR Somalia OR Tajikistan OR Tanzania OR Togo OR Uganda OR Zimbabwe OR Albania OR Armenia OR Belize OR Bhutan OR Bolivia OR Cameroon OR Congo, Rep. OR Côte d'Ivoire OR Djibouti OR Egypt OR El Salvador OR Fiji OR Georgia OR Ghana OR Guatemala OR Guyana OR Honduras OR Indonesia OR India OR Iraq OR Kiribati OR Kosovo OR Lao PDR OR Lesotho OR Marshall Islands OR Micronesia OR Moldova OR Mongolia OR Morocco OR Nicaragua OR Nigeria OR Pakistan OR Papua New Guinea OR Paraguay OR Philippines OR Samoa OR São Tomé and Principe OR Senegal OR Solomon Islands OR South Sudan OR Sri Lanka OR Sudan OR Swaziland OR Syrian Arab Republic OR Syria OR Timor-Leste OR Tonga OR Ukraine OR Uzbekistan OR Vanuatu OR Vietnam OR West Bank and Gaza OR Yemen OR Zambia

3/6



S5	S1 OR S2 OR S3 OR S4	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,074,869	Edit
S4	(MH "Family")	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	67,828	Edit
S3	TI caregiver* OR "family caregiver*" OR guardian* OR "informal caregiver*" OR family OR families	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,048,035	Edit
S2	AB caregiver* OR "family caregiver*" OR guardian* OR "informal caregiver*" OR family OR families	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,067,288	Edit
S1	(MH "Caregivers")	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	27,073	Edit

7.5 Appendix 5: Low- and middle-income countries as defined by the World Bank

The World Bank Group's classification of countries by income groups. Available from:

http://data.worldbank.org/about/country-classifications/country-and-lending-groups

LOW INCOME COUNTRIES ($1035 or less)		
Afghanistan	Guinea-Bissau	Sierra Leone
Burkina Faso	Haiti	Somalia
Burundi	Korea, Dem. People's Rep.	South Sudan
Central African Republic	Liberia	Sudan
Chad	Madagascar	Syrian Arab Republic
Congo, Dem. Rep	Malawi	Tajikistan
Eritrea	Mali	Togo
Ethiopia	Mozambique	Uganda
Gambia, The	Niger	Yemen, Rep.
Guinea	Rwanda	

LOWER-MIDDLE INCOME ECONOMIES ($1,036 TO $4,045)		
Angola	Honduras	Papua New Guinea
Algeria	India	Philippines
Bangladesh	Kenya	São Tomé and Principe
Benin	Kiribati	Senegal
Bhutan	Kyrgyz Republic	Solomon Islands
Bolivia	Lao PDR	Sri Lanka
Cabo Verde	Lesotho	Tanzania
Cambodia	Mauritania	Timor-Leste
Cameroon	Micronesia, Fed. Sts.	Tunisia
Comoros	Moldova	Ukraine
Congo, Rep.	Mongolia	Uzbekistan
Côte d'Ivoire	Morocco	Vanuatu
Djibouti	Myanmar	Vietnam
Egypt, Arab Rep.	Nepal	West Bank and Gaza
El Salvador	Nicaragua	Zambia
Eswatini	Nigeria	Zimbabwe
Ghana	Pakistan	

UPPER-MIDDLE-INCOME ECONOMIES ($4,046 TO $12,535)

Albania	Fiji	Montenegro
American Samoa	Gabon	Namibia
Argentina	Georgia	North Macedonia
Armenia	Grenada	Paraguay
Azerbaijan	Guatemala	Peru
Belarus	Guyana	Russian Federation
Belize	Indonesia	Samoa
Bosnia and Herzegovina	Iran, Islamic Rep.	Serbia
Botswana	Iraq	South Africa
Brazil	Jamaica	St. Lucia
Bulgaria	Jordan	St. Vincent and the Grenadines
China	Kazakhstan	Suriname
Colombia	Kosovo	Thailand
Costa Rica	Lebanon	Tonga
Cuba	Libya	Turkey
Dominica	Malaysia	Turkmenistan
Dominican Republic	Maldives	Tuvalu
Equatorial Guinea	Marshall Islands	Venezuela, RB
Ecuador	Mexico	

7.6 Appendix 6: CASP Quality Appraisal Tool

Item	Salmon and McLaws 2015	Islam et. al 2007	Comments
Is there a clear statement of research aims?	• Goal of research is to explore health care worker (HCW) barriers to hand-hygiene in Vietnam. • Important because hand hygiene central to HCW duty of care to protect patients yet HCW in Vietnam struggle with compliance.	• Goal of the research to explore family caregivers perceptions and practices related to disease transmission in hospitals. • Important because family caregivers are integral to patient care in Bangladeshi public hospitals and perform patient care tasks.	While its easy to decipher the aims of the research they are not explicitly stated in either study.
Is Qualitative methodology appropriate?	Yes; qualitative appropriate methodology as study aims to explore '*experience*' and '*perceptions*'.	Yes; qualitative appropriate methodology as study aims to explore individual '*perceptions*'.	Both studies are looking at experience and perception which are congruent with qualitative research.
Is the research design appropriate to address aims of the research	• Authors have not explicitly explained why they chose this methodology. They do however explain the need for an exploratory study:	• Authors have not explicitly explained why they chose this methodology. They do explain that: • There is little information about	The design of both studies is appropriate to address the research aims.

	• There is scant hospital acquired infection (HAI) data available, • Little understanding of the determinants of hand hygiene behavior. • On this basis they wanted to explore barriers to hand hygiene.	what care is provided by caregivers • What their exposure to infectious agents, • Their perceptions of disease transmission, • Their hygiene practices. The authors express their desire to identify caregivers specific exposures and actual practices and understand their perceptions with a view then prioritize areas for interventions to reduce transmission of infectious agents between patients and family caregivers.	
Recruitment strategy appropriate to aims of research	There is no detailed information about how or why these participants were selected for the study, if they were most suitable or if anyone was excluded. • At each hospital, participants were invited from selected hospital departments,	There is no detailed information about how or why these participants were selected for the study, if they were most suitable or if anyone was excluded. • Family care- givers who had spent at least 5 hours per day in the hospital for at least 2	This appears to be a weaker element of both studies as the recruitment strategy and inclusion/ exclusion criteria is not made explicitly clear in both. • It appears purposive sampling was

	and focus discussion groups were held separately for physicians and nurses. • Participation was voluntary • To encourage participation, a modest incentive was offered to cover costs incurred at each health care facility	days so that the respondents had some experience of patient care activities.	used in the Salmon (2015) study. • Islam et. al (2014) for the observation portion o the study there is an explanation of when observations were undertaken. • Islam et. al 2014 identifies some exclusion/ inclusion criteria for the interviews and the units from which the care givers were drawn. Its not expressly clear why these were chosen.
Data collected in a way that addressed the research issue	Setting: hospitals in Vietnam • 12 Focus groups were conducted between	Setting: Bangladeshi hospitals • For the observations, timing was varied according to frequency	• Setting is clear • How data was collected in both is clear • Justifications of the methods

	August 2010 and May 2011. - Each focus group had approximately 8-12 participants. - 60 minutes per focus group. - Data on HCW sex, age, and years of experience were not collected. - Audiotapes and transcription	and nature of caregiving. Observation hours were split between daytime hours (9:00 a.m. to 2:30 p.m.), when there was more activity; evening hours (3:30 p.m. to 9:00 p.m.), when there was reduced activity; and at night (10:00 p.m. to 12:30 a.m.), when there was even less activity. - Each observer was responsible for observing a maximum of 10 patients and their respective caregivers and taking detailed handwritten notes - 2 in-depth interviews with family caregivers: 6 from pediatric wards; 6 from adult, male, medicine wards.	chosen is not expressly explain in either study - Form of the data is clear hand written notes/ audiotapes etc. - Data saturation not discussed

Relationship between researcher and participants adequately considered	The researchers do not critically examine their role in the process. • They state that one researcher trained a local interviewer and concurrent translation was provided throughout the process. • The study acknowledges that professional hierarchy may have been present within the group discussions, including the possibility that participants might have answered according to the group's social norms for hand hygiene at the hospital as a limitation of the study but does not explore this in relation to their own role as researchers.	The researchers do not critically examine their role in the process.	This is under examined in both studies. • A critical omission given the possibility for the Hawthorne effect in Islam *et. al* 2014 • The possibility for social norms of hierarchy in Vietnam interviews and its impact on participant answers in interviews.

Have ethical issues been taken into consideration	Ethical approval was obtained from the: • National Institute of Hygiene and Epidemiology (NIHE) in Hanoi • University of New South Wales in Australia. • Ethical approval from the NIHE was accepted by each of the 6 hospitals • Informal consent was obtained from all HCWs to participate. • The NIHE liaised with the hospitals and organized the focus discussion group schedule	Ethical standards identified: • Consent obtained from the hospital authorities for the study. • Informed written consent from all respondents. • Study protocol reviewed and approved by the International Centre for Diarrheal Disease Research • Ethical Review Committee approval • Centers for Disease Control and Prevention's Human Subject Research Office approval	Salmon et. al 2015 state that 'informal' consent was obtained from participants- query is this a typo for 'informed'?
Was data analysis sufficiently rigorous	• Audiotapes transcribed verbatim using standard word processing software. • Transcripts proofread	• Primary author reviewed the observation field notes • List of all observed patient care activities	Researchers own role in bias of the findings not explored in either study

	• Translated to English by NIHE staff • Transcripts were read independently by M.L.M. and S.S., who • Identified list of themes and subthemes after reading a sample of interviews. • Ambiguity in translation, 1 researcher was able to check the original transcripts in Vietnamese (S.S.), and 1 researcher (M.L.M.) was present and received concurrent translation for all interviews. • Transcripts were not examined separately by profession. • Themes and subthemes were agreed on, • Read and coded the remaining transcripts. • A thematic framework around the codes was	performed by family caregivers. • Frequency of each caregiving activity. • Transcribed the in-depth interviews verbatim. • Read interviews line by line • Developed a code list and a definition for each code. • New information that did not fit with the existing codes identified • New codes created and shared them with team to reach a consensus on new code definitions. • All the data inputted into text-organizing software according to the code list • Reviewed the coded data to capture the main research themes and concepts.	Salmon et. al NIHE staff undertook translation ? not independent- although secondary review by external researchers How themes emerged unclear

	tested with a second sample of transcripts for modification. - The framework was tested against the full sample and refined.		
Is there a clear statement of findings	- Results presented according to identified themes	- Results explicitly presented in table format and according to themes - Credibility of findings discussed - Findings discussed in relation to original research question	
How valuable is the research	Study identifies adherence to and understanding of hand hygiene in Vietnam remains poor. Discussion on relationship to wider policy implications and limitations expressly identified.	Study identified that family caregivers are at risk for hospital-acquired infection from repeated and close exposures to patients in hospital wards because these frequent contacts could transmit infectious agents.	

7.7 Appendix 7: Data extraction tool

Review title How do informal caregivers experience their role in providing patient care in hospitals in low- and middle-income countries? A qualitative meta-synthesis.

General Information

Date form completed *(dd/mm/yyyy)*	21/04/2020
Name/ID of person extracting data	Unarose Hogan
Reference citation (e.g. Medline)	Family caregivers in public tertiary care hospitals in Bangladesh: Risks and opportunities for infection control
URL	http://www.ncbi.nlm.nih.gov/pubmed/24406254
Study author contact details	saiful@icddrb.org.
Publication type	Journal Article
Notes: Bangladesh Family Care Giver INFECTION PREVENTION AND CONTROL risk study-Observation + Interview	

Overview:

Aim of study	To explore family caregivers perceptions and practices related to disease transmission in hospitals	Pg. 305 Abstract
Design	Observational ethnographic	Pg. 306 Methods
Conceptual model of theory used	None specified	

Key findings	2,065 episodes of caregiving observed by family members 1,544 episodes involving close patient contact Family caregivers washed their hands with soap on 4 occasions.	Pg. 307 Table
Start date	April 2007	Pg. 306 Methods
End date	May 2007	Pg. 306 Methods
Ethical approval needed/ obtained for study	✓ Yes No • Consent obtained from the hospital authorities for the study. • Informed written consent from all respondents. • Study protocol reviewed and approved by the International Centre for Diarrheal Disease Research • Ethical Review Committee approval Centres for Disease Control and Prevention's Human Subject Research Office approval	Pg. 306 Ethical Considerations

Sample	Observation: family caregivers in hospitals in Bangladesh	Pg. 306 Methods
	Interviews: 12 family caregivers 12 in 6 from paediatric wards; 6 from adult, male, medicine wards.	
Inclusion criteria	Family caregivers who had spent at least 5 hours per day in the hospital for at least 2 days so that the respondents had some experience of patient care activities.	Pg. 306 Methods
Exclusion Criteria	Non family care givers	
Selection rationale	So the caregivers had adequate exposure to provide care	

Size	Observation not specified Interview 12	Pg. 306 Methods
Setting	1 pediatric ward 1 adult male medicine ward In each of 3 tertiary care public teaching hospitals Dhaka, Bangladesh Rajshahi Medical College Hospital (RMCH) Faridpur Medical College Hospital (FMCH), Suhrawardi Medical College Hospital (SMCH)	Pg. 306 Methods
Method of recruitment of participants	Observation: no recruitment Interview: not specified- possible convenience	Pg. 306 Methods
Informed consent obtained	☑ Yes ☐ No ☐ Unclear Informed written consent from all respondents for interviews.	Pg. 306 Ethical Considerations
Data Collection	• Observation hours were split between daytime hours (9:00 a.m. to 2:30 p.m.), when there was more activity; evening hours (3:30 p.m. to 9:00 p.m.), when there was reduced activity; and at night (10:00 p.m. to 12:30 a.m.), when there was even less activity. • Each observer was responsible for observing a maximum of 10 patients and their respective caregivers and taking detailed handwritten notes • 2 in-depth interviews with family caregivers: 6 from pediatric wards; 6 from adult, male, medicine wards.	Pg. 306 Methods

Role of Researcher	For observation: impartial observation 5 researchers Not explicitly expressed for interviews		Pg. 306 Methods
Field Work	Yes	Hospital observation	Pg. 306 Methods
Data Analysis	• Primary author reviewed the observation field notes • List of all observed patient care activities performed by family caregivers. • Frequency of each caregiving activity. • Transcribed the in-depth interviews verbatim. • Read interviews line by line • Developed a code list and a definition for each code. • New information that did not fit with the existing codes identified • New codes created and shared them with team to reach a consensus on new code definitions. • All the data inputted into text-organising software according to the code list • Reviewed the coded data to capture the main research themes and concepts.		Pg. 306 Methods
Researcher Potential Bias	Not addressed		Pg. 306 Methods
Reflexivity	Not addressed		
Themes	Behavioural barriers to hand hygiene - Knowledge translation: daily practices did not reflect the prevention methods they described. They perceived that washing hands with soap could reduce disease transmission; however, we rarely observed caregivers washing their hands with soap after cleaning patients' anuses, vomit, or mucus		Pg. 308 Care Pg. 309 Discussion
	Knowledge barriers to hand hygiene: - Inconsistent understanding of disease transmission pathways		Pg. 309 Discussion

	Structural barriers to hand hygiene: - 10 hand washing stations for family caregivers in the study wards - 2 of them had running water - none had hospital-supplied soap. - hospital infrastructure - lack of water - lack of hand washing stations	Pg. 309 Discussion Pg. 307 Findings Cleaning Care
Key Conclusions	-This study identified that family caregivers are at risk of hospital-acquired infection from repeated and close exposures to patients in hospital wards because these frequent contacts could transmit infectious agents. -Public hospitals that are overcrowded and lack adequate handwashing infrastructure, sanitary facilities and infection control programmes and depend on family caregivers to provide direct patient care create an environment that increases risk of the transmission of infections from patients to family caregivers. - Hand washing rarely performed despite close patient contact	p. 308 Discussion p.309 Discussion
Implications for policy and practice	Policy -Explore the incentive structure of hospital administrators and health care workers in Bangladeshi hospitals could identify potential strategies to use incentives to improve patient care	Pg. 309 Discussion

	Practice Strategies to enhance motivation and retention along with financial incentives and in-service training for health care workers have improved collaboration and communication among health care workers, reduced health care worker occupational risks and improved direct patient care in other settings Engage family caregivers, in interventions to prevent hospital-acquired infections Health education intervention that uses culturally appropriate messages based on awareness of infections and the importance of hand hygiene could be developed. Feasibility and cost-efficacy of alcohol hand sanitiser	Pg. 309 Discussion
Further research	Pilot interventions in some public tertiary care hospitals in Bangladesh could explore the feasibility, acceptability and effectiveness of such an approach Feasibility and cost-efficacy of alcohol hand sanitiser Research to explore the incentive structure of hospital administrators and health care workers in Bangladeshi hospitals could identify potential strategies to use incentives to improve patient care. To generate an evidence base for protecting family caregivers, future surveillance for hospital-acquired illness should also consider including family caregivers to identify the rate of infection among this group.	Pg. 309 Discussion

Authors' reported limitations of the study's methods/results	Conducted this study in only three government public tertiary care hospitals and had limited observation time, Each researcher was responsible for observing multiple patients and caregivers; he/she might have missed activities that occurred simultaneously. Therefore, the observational methods used in this study may underestimate the actual frequency of caregiving activities performed by family caregivers. Research to explore strategies to improve family caregivers' hand hygiene could reduce their exposure to infectious agents.	Pg. 308/9 Discussion Pg. 307 Cleaning Care

Notes:

Hand washing infrequently performed

Some knowledge of the importance of handwashing by carers identified

Two sinks with running water, no soap

7.8 Appendix 8: Informational poster

Understanding the role of informal caregivers in infection prevention and control in hospitals in low and middle income countries; a focused ethnographic study.

CDC Public Photo Library

What is this about?

This is about research study that will take place in this hospital that will look at what care informal caregivers provide to their family members on a daily basis in the hospital.

Do I have to take part?

No. Its completely up to you if you want to take part. If you want to take part you can let a nurse or a doctor know or you can text the phone number below or sign your name in a box on your ward at the nurses station. .

What will I be asked to do if I take part?

If you would like to take part no further action is needed from you. You will be asked to continue your day as normal and the researcher will observe what you are doing and take notes. You may be asked about your opinion from time to time and for an interview, for a more detailed conversation lasting about one hour.

Who is doing this study?

Unarose Hogan, a PhD student at university of Lancaster UK.

Where can I get more information?

If you would like more information please pick up an information sheet that are available at the nurses station in your ward or text the number below.

Lancaster University

For any further information, to sign up or to register a concern please feel free to contact this number: 0163 3677318

7.9 Appendix 9: Informal caregiver participant booklet

Participant information leaflet

A study

Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; A focused ethnographic study.

Before you decide whether to participate in this study, it is important for you to understand why the study is being conducted and what is involved. Please take the time to read the following information carefully, and discuss it with others if you wish. If anything is not clear, or if you would like more information, please call the researcher on the number on 0163 3677318 to talk to a member of our study team or email uhogan@lancaster.ac.uk

About this study

The goal of the study is to find out more about the role of informal caregivers in the hospital. We hope to understand what patient care practices you may preform as an informal caregivers in your daily routine and your perspective on infection control. As a health care worker we hope to understand your perspective on the role of the informal caregiver and how you may interact for infection control. We will do this through observing practices in the clinical unit and also through interviews.

Why is this study needed?

Because hospital acquired infections are a leading cause of patient mortality and morbidity and preventing hospital-acquired infections can be achieved through good infection control practices. A majority of policies, education, training for infection control practices generally target the health care worker and may ignore the potentially important role of informal caregivers in contributing to safer patient care practices. We would like to explore this further to develop an understanding of what the actual role of informal caregivers is in patient care provision and what this means for infection control

Do I have to take part?

No, it is completely up to you.
If you decide NOT to take part you will be asked to sign an OPT OUT form available in this booklet. If you decide to take part you are free to withdraw at any time, without giving a reason.

Why have I been approached?

We are inviting informal caregivers who are taking care of a patient in hospital in Vietnam.

You are eligible to take part in the study if you:

- Are aged 18 or over.
- Have been taking care of a patient in the hospital for two days or more
- Are willing to have a researcher observe your daily life in the hospital
- Are willing to potentially have an interview with the researcher through a translator

You are not eligible to take part in the study if you:

- Are caring for a patient in the emergency room, out patients

We are also inviting health care workers to be part of this study.

You are eligible to take part in the study if you:

- Are aged 18 or over.
- Are a healthcare professional employed at the study hospital, clinical staff and infection control teams of the hospital
- Are willing to have an interview with the researcher through a translator

Will my data be identified?

Your privacy will be protected at all times and the steps taken to ensure confidentiality are detailed below:

What will happen the results?

The results will be summarised and reported in a PhD thesis and may be submitted for publication in an academic or professional journal. The material will also be used to make presentations at conferences.

Lancaster University

Participant information leaflet

A study

Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; A focused ethnographic study.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits?

Although you may find participating interesting, there are no immediate direct benefit in taking part.

Who has reviewed this project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University.

Who is conducting this research?

My name is Unarose Hogan and I am conducting this research as a PhD Public Health student at Lancaster University, United Kingdom.

Where can I obtain more information?

If you have any questions about the study, please contact any of the following researchers:

Unarose Hogan uhogan@lancaster.ac.uk

Dr. Catherine Walshe c.walshe@lancaster.ac.uk

Dr. Amanda Bingley a.bingley@Lancaster.ac.uk

Complaints

If you wish to speak to someone outside of the Doctoral Programme, you may also contact Dr. Thuy Nguyen from the hospital infection control department

☎ Thuy Nguyen Tel: +84 (0)1524 593746

@ Deputy Director Infection Control Department: nguyen.thuy@gmail.com

Thank you for taking the time to read this information sheet.

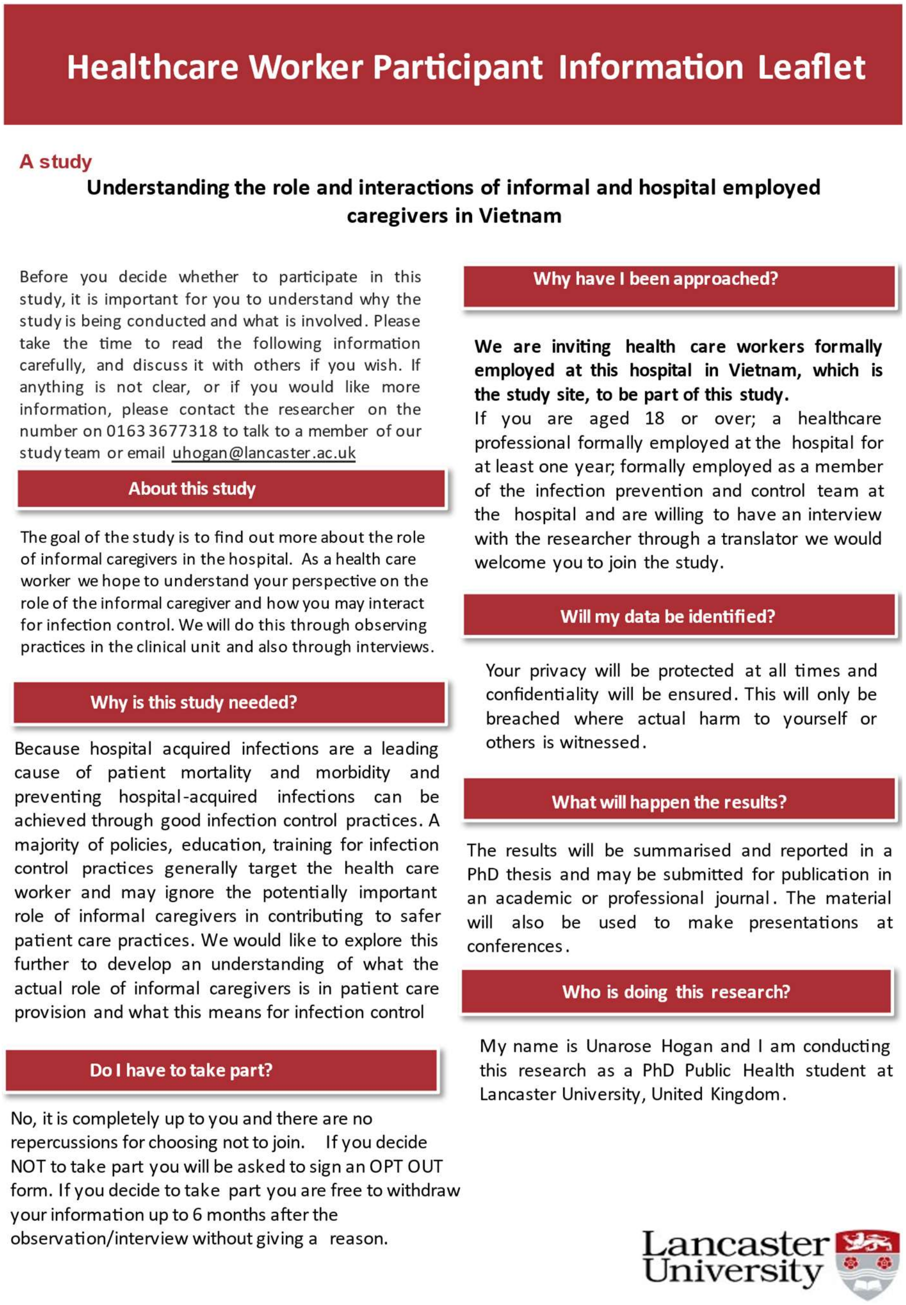
Resources in event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Vietnam associate of Publlic Health Institutes which has contact details for research concerns **www.nihe.org.vn**

Lancaster University

7.10 Appendix 10: Healthcare worker participant booklet



Healthcare Worker Participant Information Leaflet

A study

Understanding the role and interactions of informal and hospital employed caregivers in Vietnam

Before you decide whether to participate in this study, it is important for you to understand why the study is being conducted and what is involved. Please take the time to read the following information carefully, and discuss it with others if you wish. If anything is not clear, or if you would like more information, please contact the researcher on the number on 0163 3677318 to talk to a member of our study team or email uhogan@lancaster.ac.uk

About this study

The goal of the study is to find out more about the role of informal caregivers in the hospital. As a health care worker we hope to understand your perspective on the role of the informal caregiver and how you may interact for infection control. We will do this through observing practices in the clinical unit and also through interviews.

Why is this study needed?

Because hospital acquired infections are a leading cause of patient mortality and morbidity and preventing hospital-acquired infections can be achieved through good infection control practices. A majority of policies, education, training for infection control practices generally target the health care worker and may ignore the potentially important role of informal caregivers in contributing to safer patient care practices. We would like to explore this further to develop an understanding of what the actual role of informal caregivers is in patient care provision and what this means for infection control

Do I have to take part?

No, it is completely up to you and there are no repercussions for choosing not to join. If you decide NOT to take part you will be asked to sign an OPT OUT form. If you decide to take part you are free to withdraw your information up to 6 months after the observation/interview without giving a reason.

Why have I been approached?

We are inviting health care workers formally employed at this hospital in Vietnam, which is the study site, to be part of this study.

If you are aged 18 or over; a healthcare professional formally employed at the hospital for at least one year; formally employed as a member of the infection prevention and control team at the hospital and are willing to have an interview with the researcher through a translator we would welcome you to join the study.

Will my data be identified?

Your privacy will be protected at all times and confidentiality will be ensured. This will only be breached where actual harm to yourself or others is witnessed.

What will happen the results?

The results will be summarised and reported in a PhD thesis and may be submitted for publication in an academic or professional journal. The material will also be used to make presentations at conferences.

Who is doing this research?

My name is Unarose Hogan and I am conducting this research as a PhD Public Health student at Lancaster University, United Kingdom.

Lancaster University

Health Care Worker Participant Information Leaflet

A study

Understanding the role and interactions of informal and hospital employed caregivers in Vietnam

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits?

Although you may find participating interesting, there are no immediate direct benefit in taking part.

Who has reviewed this project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. It has also been reviewed and approved by the hospital ethics board at this Vietnamese hospital.

Where can I obtain more information?

If you have any questions about the study, please contact any of the following researchers:

Unarose Hogan uhogan@lancaster.ac.uk

Dr. Catherine Walshe c.walshe@lancaster.ac.uk

Dr. Amanda Bingley a.bingley@Lancaster.ac.uk

Complaints

If you wish to speak to someone outside of the Doctoral Programme, you may also contact Dr. Thuy Nguyen from the hospital infection control department

☎ Thuy Nguyen Tel: +84 (0)1524 593746

@ Deputy Director Infection Control Department:
nguyen.thuy@gmail.com

☎ Prof. roger Pickup Tel: +44 1524 593746

@ Associate Dean for Research, Faculty of Health and Medicine, Division of Biomedical and Life Sciences, Lancaster University, Lancaster,
LA1 4YD.
r.pickup@Lancaster.ac.uk

Thank you for taking the time to read this information sheet.

Resources in event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.
Vietnam associate of Public Health Institutes which has contact details for research concerns
www.nihe.org.vn
Or contact Dr. Thuy Nguyen at this hospital who can advise about other resources.

For further information please

TEXT 0163 3677318

"1" To register an interest in the study and receive further information
"2" To request further information about the study
"3" To report a problem or concern about this study

Lancaster University

7.11 Appendix 11: Healthcare workers interview topic guide

Welcome and thank you for agreeing to take part in this interview in your hospital. As we explained in this morning's meeting, we appreciate your participation and are keen to hear your perspective. We anticipate the interview will take a maximum of one hour and wish to thank you for your time.

Introduction: Welcome and thank you for agreeing to take part in this interview in your hospital. We are here today as part of a research study that you have expressed interest in being involved. The focus of the study is on the role of informal caregivers in infection prevention and control in this hospital. As an informal caregiver in the hospital we think your perspective is invaluable for helping to understand these roles. If you all agree, we will tape this discussion so the conversation may be transcribed at a later point for use in data analysis .If you all agree, we will tape this discussion so the conversation may be transcribed at a later point for use in data analysis.

Anonymity: This discussion is anonymous; recordings will be safely locked on an encrypted recording device until they are transcribed at which point and will then be deleted. Transcribed notes of

the interview will contain no information that allows anyone to be identified. If you have any questions, please feel free to ask them. If you agree to proceed we would invite you to complete this consent form. We would also like to advice you that you are free to withdraw at any point up to six months after this interview.

Greetings

First, I'd like to introduce myself and my credentials and my association with this research study.

General/Opening

- How would you describe your interactions with informal caregivers on your unit?
- What patient care do you observe informal caregivers providing routinely?

Guiding Topics

- What is your expectation of informal caregivers to provide patient care activities-do you usually expect there are certain patient care activities that they should perform?
- Do you consider you have a role in supporting informal caregivers and if yes, what is that role? *Education, advice etc.*
- Do you encourage informal caregivers to have access to any personal protective equipment?
- Do you consider it your role as healthcare worker to demonstrate patient care, waste disposal, use of personal protective equipment to the informal caregiver?
- Do you provide the caregiver any particular advice specific to infection control?
- If a patient has a confirmed hospital acquired infection, is the caregiver informed?
- If you have a role in deciding staffing numbers for the day, do you factor in the numbers of informal caregivers into the work load?
- Do you value/ appreciate the work the informal caregiver provides?
- Do you ever ask the informal caregiver for information about the patient?
- If a patient has an open wound do you provide advice to the caregiver for how to prevent infection of that wound?
- Do you know if the caregivers have access to personal hygiene facilities for themselves?
- Are informal caregivers ever restricted from being in the clinical unit? *If yes when and for what reasons?*

7.12 Appendix 12: Informal caregiver interview topic guide

Welcome and thank you for agreeing to take part in this interview in your hospital. As we explained in this morning’s meeting, we appreciate your participation and are keen to hear your perspective. We anticipate the interview will take a maximum of one hour and wish to thank you for your time.

Introduction: Welcome and thank you for agreeing to take part in this interview in your hospital. We are here today as part of a research study that you have expressed interest in being involved. The focus of the study is on the role of informal caregivers in infection prevention and control in this hospital. As an informal caregiver in the hospital we think your perspective is invaluable for helping to understand these roles. If you all agree, we will tape this discussion so the conversation may be transcribed at a later point for use in data analysis .If you all agree, we will tape this discussion so the conversation may be transcribed at a later point for use in data analysis.

Anonymity: This discussion is anonymous; recordings will be safely locked on an encrypted recording device until they are transcribed at which point and will then be deleted. Transcribed notes of the interview will contain no information that allows anyone to be identified. If you have any questions, please feel free to ask them. If you agree to proceed we would invite you to complete this consent form. We would also like to advice you that you are free to withdraw at any point up to six months after this interview.

Greetings

First, I’d like to introduce myself and my credentials and my association with this research study.

General/Opening

- How do you describe your role as an informal caregiver
- Can you describe what your typical do on a day in the hopsital

- Are you familiar with the term infection prevention and control

Guiding Topics

- Patient care activities- washing, feeding dressing, wound dressings etc.
- Access to any personal protective equipment- when are these used? Received any instruction on when to use these and if so by whom?
- Access to structural materials- *sinks, waste disposal*
- Caregiver living and sleeping arrangements- cooking facilities, sleeping facilities onsite in the hospital?
- Anything you would change about the caregiver situation in the hospital?
- Sole responsibility for the patient- are you sole caregiver or share responsibilities with another?
- Perspective on the healthcare worker- did they provide advice? Any barriers to communication? Any training provided by healthcare worker for infection control?
- Do you feel valued in the hospital for your work? *Appreciated,*
- Infection control priorities- is it familiar? Is it a priority?
- Have you ever been exposed to blood or bodily fluid when caring for your relative?
- Do caregivers help patients other than the one they are primary caregiver for?
- Discussion based on observations and clarification of any practices witnessed.

7.13 Appendix 13: Ethical approval form Lancaster University

Please note ethics was received from the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. In addition, ethics approval in Vietnam was received through an institutional review board approval process at the hospital where the research was conducted. This involved presenting the proposed project to an ethics panel from the hospital and defence of its design, presentation of proposal and all associated documentation in Vietnamese, presentation of researcher credentials and immigration status in Vietnam.

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Title of Project: Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; a focused ethnographic study.

Name of applicant/researcher: Unarose Hogan

ACP ID number (if applicable)*: Funding source (if applicable)

Grant code (if applicable):

*If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].

Type of study

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒Includes *direct* involvement by human subjects.

Complete sections one, *three* and four of this form

SECTION ONE

1. Appointment/position held by applicant and Division within FHM

International Advisor Infection Prevention and Control for Centre for Disease Control, Global Health Security Project, Vietnam. Unarose Hogan is an international infection prevention and control expert currently providing advice to the Ministry of Health in Vietnam and six national Vietnamese hospitals for strengthening infection prevention and control systems in preparedness for epidemics under the World Health Organization framework for International Health Regulations. Formerly she held the position as Chief of Infection Prevention and Control throughout the West Africa Ebola response with the United Nations Mission Emergency Ebola Response (UNMEER). She served as chief infection control educator with New York University in Rwanda and held an appointment as academic lecturer for infection control and patient safety with University of East Anglia, UK. She has held a range of positions in infection control and health systems strengthening with the World Health Organization, Irish Aid and the German bi-lateral GIZ; across Albania, Sierra Leone, Liberia, Guinea, Malawi, Uganda, Tanzania, Rwanda and Kenya. She is a registered nurse maintaining active licenses in both the UK and Ireland. Clinically she has assumed a range of roles as infection control nurse across the UK, Ireland and South Africa. She holds a position as Vice-Chair of the Infection Control Africa Network; reviewer for the international journal of infection control and is a member of the World Health Organization global advisory group for infection prevention for morbidity management for lymphatic filariasis. Position within FHM: PhD Student Public Health

2. Contact information for applicant:

E-mail: unarose@campus.ie **Telephone**: +353863797232

Address: Urra, Ballycommon, Nenagh, Co. Tipperary, Ireland.

3. Names and appointments of all members of the research team (including degree where applicable)

Dr Amanda Bingley Lecturer, Division of Health Research, Faculty of Health & Medicine

Prof. Catherine Walshe Reader in Palliative Care, Division of Health Research, Faculty of Health & Medicine.

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma   Masters by research   PhD Thesis   PhD Pall. Care

☒ PhD Pub. Health   PhD Org. Health & Well Being   PhD Mental Health   MD

DClinPsy SRP   [if SRP Service Evaluation, please also indicate here:]   DClinPsy Thesis

4. Project supervisor(s), if different from applicant:

5. Appointment held by supervisor(s) and institution(s) where based (if applicable):

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management](#) *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

6a. Is the secondary data you will be using in the public domain?

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Informal caregivers of patients in hospitals in low and middle-income countries often assume a direct role in providing patient care, owing to cultural and social norms and a lack of human resources for health. Any caregiving practice presents a potential risk for infection transmission in a hospital setting, however, there is insufficient published literature exploring this risk as it relates to the caregiving role of informal caregivers. This study proposes to investigate the role of the informal caregiver in infection control in a hospital in Vietnam to address this gap. Using a focused ethnographic approach with a sample of 10-20 informal caregivers and 8-15 healthcare workers, participant observation and semi-structured interviews will be conducted. Data will be analysed along an inductive paradigm informed by Roper and Shapira's framework for analysis and situated in a systems theoretical perspective. The findings will inform a better understanding of the utilisation of the role of the informal caregiver for improved INFECTION PREVENTION AND CONTROL practices

2. Anticipated project dates (month and year only)

Start date: 01/01/2018 End date01/09/2019

Data Collection and Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

The participants for this study will include 10-20 potential informal caregiver participants and 8-15 potential healthcare worker participants in the medical and surgical clinical units of the hospital, which are the observation sites for this study. The inclusion criteria for the informal caregiver participants includes; meeting the World Health Organisation WHO (2004) definition if an informal caregiver which is any person without formal health training who is not employed by the hospital facility and is onsite in capacity as ‘carer’ or ‘guardian’ of a person known to them who is admitted to the facility as a patient. Additional inclusion criteria for the informal caregiver participants includes those caregivers of patients who have been admitted to the hospital for longer than 48 hours. The rationale for this is to include patients who are at risk of developing a hospital acquired infection which aligned with WHO's definition for a hospital-acquired infection which is an infection presenting more than 48 hours after admission to a hospital that was not present nor incubating at the time of admission. The exclusion criteria among the informal caregiver participants are caregivers of patients who are in non- inpatient settings such as outpatients, clinics and emergency rooms who may not have the experience of providing inpatient care for a sufficient duration and informal caregivers under 18 years old for protection reasons. Among the healthcare worker participants those who those who have been working for more than one year clinically within the hospital units which are among the study sites and also healthcare workers from the infection control departments of the hospitals will be eligible for inclusion. The rationale for this is seeking information-rich sources who will have previous experience of engaging with informal caregivers. Final sample sizes will be determined by the participant's willingness to engage and share experiences to the point of data saturation when all relevant topics have been investigated and no new interpretations are generated from additional participation. As English language literacy is low in Vietnam all conversations, interviews will need to be conducted with a translator. For this purpose, a qualified medical Vietnamese- English translator will be employed throughout the course of this study. To capture a sample of information-rich potential informal caregivers and healthcare worker participants to explore the research question, a mixed purposive sampling approach will be employed, using both criterion and snowball sampling. Criterion sampling will draw generalisations about the sample and snowball sampling can assist in finding appropriate information-rich cases through referral. Purposive sampling aims to gather information-rich cases and will include seeking caregivers with a range of experiences to understand their varying perspectives. Among the informal caregiver participants, maximum variability across a number of different domains will be sought including length of caregiving experience and type of illness. Among the potential healthcare worker sample, those who have experience of engaging with patients and their family members will be sought. Criterion sampling is helpful in this study to identify and select cases that meet the predetermined criterion of importance as outlined in the inclusion and exclusion criteria. Snowball sampling will allow the identification of cases of interests from other informal caregiver and healthcare workers with similar characteristics. This iterative approach can facilitate triangulation and flexibility where sampling and re-sampling may be needed to ensure theoretical saturation occurs.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

A healthcare worker from the hospital infection control department will act as a recruitment contact person to facilitate the identification of potential participants for this study. This will be negotiated with hospital management in advance of commencing the data collection and the researcher will establish a rapport with the contact person in an effort to have them champion the research for participation and publicising at the hospital. The rationale for this is to respect established hierarchical structures within Vietnamese hospitals where the infection control department have oversight over all infection control related research within the hospital. Given the low degree of English fluency recruitment for the services of the qualified medical translator will be sought for the duration of the study who will assist with all verbal interpretations and written translations.

The study will be publicised within the hospital for up to two weeks in advance of commencing, with the rationale that a period longer than that may be redundant in an acute inpatient unit where discharges of patients are likely. The posters will be continuously available throughout the full duration of the study period as new unit admissions are likely, in Vietnamese about the study, will be placed in visible locations around the medical and surgical clinical units which are the observations sites. In addition, the sleeping areas for informal caregivers (often shaded outdoor corridors adjacent to the clinical unit), the bathrooms, the cooking areas and the hospital canteen will display posters and can be seen in Appendix 1.

Potential informal caregiver participants that may be interested they can register their interest in a securely locked collection box placed at the nurses station in the clinical areas or can report this to any healthcare worker in their clinical area who will be asked to compete an interest registration slip on behalf of the patient or can text a phone number in the Vietnamese language which will be maintained by the researcher that will be dedicated to this study. The collection box will be checked daily of the hospital employed INFECTION PREVENTION AND CONTROL champion. Among those who express an interest an informal caregiver participant information sheet translated in Vietnamese will be hand delivered by the researcher or the hospital contact person and is available in Appendix 5.

Potential healthcare worker participants can also express an interest in the same secure locked collection box or can verbally report their interest to the study contact person from the hospital infection control department or directly to the researcher through texting the study dedicated phone line. Prewritten text messages with information will be available for the phone line, google translate can be used for short replies for the HCW's which can be triangulated with translation from the interpreter.

A healthcare worker participant information sheet in Vietnamese will also be made available to all healthcare workers with whom an interview will occur and all those who work in the hospital units for their information and is available in Appendix 7.

All potential participants will have sufficient time to allow them to make an informed decision about joining the study. It will be made explicit that participation is voluntary and there is no penalty for refusal to participate and that indeed they may withdraw All participants will have the opportunity to withdraw their data up to six months after the point of data collection. Throughout the research through a verbal request to the researcher or study contact person from the INFECTION PREVENTION AND CONTROL department or through the study dedicated phone line.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

As a focused ethnographic study this study will adopt the following methods of data collection:

1. Observation of informal caregivers in four clinical areas (observation sites) of a Vietnamese hospital. Multiple caregivers will be observed at once due to the open multiple bed (Nightingale ward) layout common in Vietnamese hospitals. The researcher will be mobile throughout the observation periods. Each observation episode will be of one hour duration. In a day there will be four episodes conducted amounting to four hours daily observation. In a week this amounts 20

hours/ episodes of observation. It is anticipated data collection will occur in two to four; one week long periods over a three-month timescale. Conducting the data collection in weekly episodes over a period of time will allow for initial analysis of themes and priority areas and facilitate a targeted selective observation based on these emergent priorities in subsequent phases. To capture the full breadth of the informal caregiver experience observations hours will be split over a 24 hour period with occasional night time visits based on informal caregiver schedule. Field notes will be used to record observed behaviour and activities during participant observation periods. Field notes will be used as mechanism to capture the physical environment, record direct contact between caregiver and patient, record any patient care tasks performed, record any infection control practice performed by caregivers such as handwashing or wearing personal protective equipment, any high-risk contact by the caregiver with blood, bodily fluids or open wound will be documented in the field notes. A related risk assessment form is available in Appendix 11.

2. Semi-structured interviews with informal caregivers and healthcare workers to follow up and clarify findings from observations and explore phenomena of interest will take place at the end of the week-long episodes of observations to clarify observations made and allow for further exploration. Interview schedules for informal caregivers are available in Appendix 9 and for health care workers are available in Appendix 10. The interviews will be conducted in a hospital meeting room at the infection control department. An incentive meal will be offered to all interviewees. Interviews will be tape-recorded using a digital audio recorder and transcribed verbatim when consent is provided. They will all be conducted in the Vietnamese language with a medical translator, transcribed in Vietnamese and translated to English by the same medical interpreter.
3. Reflection diary will be kept by the researcher, to explicitly recognise researcher role, identify personal biases and as a quality mechanism. Reflexive journals serve the purpose of providing contextual information to the observations recorded in the field notes. A reflexive diary is where thoughts and concepts can emerge and begin the process of interpretation of what is observed. It is an important tool for the researcher to define their role within the research as a human instrument.

Analysing focused ethnographic data requires the researcher to engage in an iterative, cyclic and self- reflective process, as preliminary interpretations are challenged, and data are continually revisited to plan for further data collection to generate new insights into the data. The process of analysing focused ethnography is characterised by the identification and classification of the data, which then progresses to generalisations and ultimately interpretation and explanation of patterns. Roper and Shapiras (2000) approach to ethnographic analysis has been successfully applied to the analysis of focused ethnography previously. This approach has been observed to be systematic, transparent and relevant to this methodology as well as being compatible with ATLAS.ti scientific software for qualitative data analysis. Raw data sources to be analysed will include observation data, field note data, interviews and reflexive journal. This first step to analysis will be the first level of coding of data into broad categories and reducing this information into descriptive labels. The descriptive labels are sorted for patterns into smaller subsets to identify codes, which show patterns of data which are alike and unalike. Emerging patterns develop which fit the data which help to explain reoccurring relationships in the data. Data, which does not easily fit, can be identified as outliers and can be used to test the rest of the data. Themes will be generated and applied to systems theory generalisations and ultimately interpretation and explanation of patterns.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

Field notes taken during participant observation periods will initially be in paper format and will be typed by the researcher at the end of each day of observation. Field notes and a personal reflection diary will be maintained using MS One Note access through a password-protected computer. Qualitative data will be generated in audio format from recorded interviews and these audio files will be stored on a password-protected computer in MP3 or WAV format. This data will be fully transcribed in Vietnamese and translated into English into MS office 2013 by the medical translator involved in the study. The medical translator will sign an agreement to maintain confidentiality of the participants and the transcripts throughout the study and is available in Appendix 4. The transcript data will be analysed using Atlas. Ti qualitative software and interview material will be housed in this program on a password-protected computer. All files will have a consistent system of naming files applied by the researcher to ensure the organised structure of documents for easy retrieval. Data will be stored on Lancaster Universities Box, a cloud storage facility which has enterprise-level file servers, authenticated identity access management a data loss prevention index and additional user encryption. Box is accessible from an individual password- protected computer. All data will be stored for the duration of the PhD programme and will be destroyed by the PhD researcher upon examination of PhD thesis which is estimated between 2019- 2020.

7. Will audio or video recording take place? no audio X video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio files from interviews will be stored in MP3 or WAV format. All audio material will be encrypted and will be deleted from the recorder as soon as transferred to a laptop and stored in the laptop until thesis submission. This data will be fully transcribed in Vietnamese and translated into English into MS office 2013 by the medical translator involved in the study. This transcript data will be analysed will using Atlas. Ti qualitative software and in the short-term interview material will be housed in this programme on a password-protected computer. The original recordings on the laptop will be deleted once the PhD thesis is assessed.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE? Supporting data will be provided in an electronic format on the journal website, with unrestricted access post- publication. Data will also be deposited in Lancaster University's institutional data repository and made freely available with an appropriate data license. Lancaster University uses Pure as the data repository which will hold, manage, preserve and provide access to data sets produced by Lancaster University research.

8b. Are there any restrictions on sharing your data ?

Due to the small sample size, even after full anonymisation, there is a small risk that participants can be identified. Therefore, supporting data will only be shared on request with genuine researchers. Access will be granted on a case-by-case basis by the Faculty of Health and Medicine.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? YES

b. Detail the procedure you will use for obtaining consent?

After ethics approval at both Lancaster university and from the ethics board in the Vietnam hospital, consent will be obtained at the recruitment phase of the research process for participant observation and at the time of data collection for semi-structured interviews. In ethnography, consent is often negotiated and renegotiated over time as the relationship between researcher and participant develops and may be withdrawn at any point throughout the process of the study. For consent to be obtained, informed participants should be fully aware of the intent of the study, its effect, the absence of any direct benefits and the potential risk of psychological distress or intrusiveness in their daily lives

For observation periods, written consent in Vietnamese will be obtained from the prime informal caregivers as the object of observation. A qualified medical interpreter will be used for all conversations with the potential participants for gaining consent. All potential participants will have sufficient time to allow them to make an informed decision about joining the study at least for forty eight hours. Consent obtained for observation periods with the informal caregivers will occur at the beginning of an observation period and remain in place throughout the study period unless the participant chooses to withdraw, the patient is discharged, dies or transferred to another facility at which point consent will cease and is available in Appendix 5. As participant observation will occur in public hospital wards in a hospital, with multiple subjects it can be anticipated that care practices will be observed by people who are not involved in the study. Opt-out consent for these additional people is a pragmatic method for obtaining consent during periods of ethnographic observations and is available in Appendix 6. For information purposes to the wider public in the hospital unit, a poster will be displayed to explain the study and the presence of the researcher there and ensuring people have an easy way to opt out through the provision of text number to ensure their choice is not violated. On the day of observation an additional measure to ensure appropriate opportunity to opt out of the observations will occour where the translator will verbally ask each caregiver at the patient bedside if they wish to opt out of the observation period.

For interviews written informed consent will be obtained from all participants and the consent form is located in Appendix 7. All participants undergoing interview will have the opportunity to review the participant information sheer, address queries to the researcher and the hospital INFECTION PREVENTION AND CONTROL gatekeeper. It will be made explicit that the choice to partake in the interview process is at the discretion of the informal caregiver and healthcare worker and can be revoked at any time up to six months after the data collection.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Overt observation of the informal caregivers could have the effect of making participants feel uncomfortable and self- conscious of their usual actions in the hospital. The sense of being ‘examined' should be mitigated through overt and unobtrusive observation and also ensuring an unobtrusive placement in the clinical unit. The participant information sheet details contacts for the participants to connect with should they wish to report any discomfort from the study.

In addition the informal interviews with informal caregivers will ask questions related to their perceptions around infection control could have the effect of expecting a change- these expectations will have to be managed by talking with participants and explaining the study and also to address any concerns it may raise the possibility of spreading infection, a concern when the research has no aspect to actually address or improve the situation through providing infection prevention and control supplies etc. Additionally having the interviews at the end of each observation period should prevent the participant being led by the questioning. Any change brought about as a result of these interview may be beneficial to the patient in the future but not in this study. Expectations and scope of the project will have to be explicitly explained at the start and situating the research in the context that the researcher hopes to ‘learn' from the participant should be negotiated. For interviews with the healthcare workers ensuring the researcher is cognisant that the interview is explained in a manner that does not contribute to a blame culture for hospital-acquired infections but rather emphasises a systems based approach. Foreigners generally in Vietnam have an esteemed status and ensuring that participant of the healthcare workers is voluntary and not assigned by senior managers will be important to assess. All participants will have the opportunity to withdraw their data up to six months after the point of data collection. This should allow sufficient time for any withdrawals without hindering the use of the collected data.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling

considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow and the steps you will take).

Risks to the researcher potentially relate to the permeability of the observer as participant role which the researcher aims to adopt in this focused ethnography. The observer as participant role facilitates the researcher to collect specific information without being an active participant in the participants setting. However, it is feasible that the researcher could be called upon by a patient in the clinical unit to assist with some practice in this naturalistic setting for which the researcher will only contact the hospital employed nurses or doctors to assist. Developing a good rapport with the clinical staff in the unit should allow the researcher to alert the clinical staff to the needs of the patients. The researcher will be accompanied during interviews with the medical translator. For some participant observations periods, it is anticipated the researcher will travel alone to the hospital, in these instances Lancasters universities lone worker guidance will be followed and a contact will be alerted to the researcher location and expected schedule. A dedicated research project mobile phone number will be used during recruitment phases and Lancaster university email will be used for any other correspondence to maintain privacy.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There may be no direct benefit to participation in this study. However, it may be an interesting project with which to engage. It is feasible that conducting this research in the hospital could have the effect of raising awareness within the clinical units and advocacy for infection control among hospital leadership around the importance of infection control.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

It is proposed that one incentive meal from the hospital canteen be provided to participants and their family member for taking part in the study throughout the observation and/or interview period as a way to offer thanks.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Confidentiality will be ensured through careful handling of the data. Informed consent will be obtained from participants. All participants will have the opportunity to withdraw their data up to six months after the point of data collection. Pseudonyms will be attributed to the interviews to ensure anonymity. Atlas.ti software will be used throughout the process.

Data collection will be conducted with a Vietnamese English translator to ensure the confidentiality of the participants the translator will be asked to sign a standard confidentiality agreement. Participants will be made fully aware of this agreement. For the informal caregivers, all publication of the data will be fully anonymised and de-identified through attribution of pseudonyms throughout the storage and analysis of data. For the healthcare workers, there is a possibility that identification of members of the small infection control teams is possible. The intention is to anonymise the contributions through de-identification of all personnel. Any limits to confidentiality for the participants will be made explicit and should any actual harm be witnessed by the researcher or if the patient or relative disclosed some harm to themselves or others.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

An identified contact person at the hospital an infection control department staff member will assist with recruitment and identification of appropriate participants and will be included in the final design of posters and participant information booklets. Their inputs are particularly sought to oversee the translation by the qualified medical interpreter to ensure that the poster reflects a vernacular contextually appropriate language and message relevant to the hospital site specifically. Consultation with the participants through an interview will inform the approach for further episodes of data collection and will drive the relevant topics to guide and direct the iterative research process.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The specific research outputs will include a PhD thesis, a summary of anonymised findings to be available to participants through video/ talks and presentations. This research is intended to be of interest to the research participants who donated their time, insights and information, the academic audience of another researcher in the field of global health, a professional audience of both clinical and hospital administration and at the policy level for interest groups such as Ministry of Health. Various publications arising from the research components in academic journals and finally conference fora related to global health topics.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

Throughout the data collection portion of the research, the following ethical issues are due consideration: Harm to the participants as result of involvement in the study is a key consideration, while it is generally considered that ethnographic research is minimally intrusive into participant's lives there exists a potential for harm.

•Broader questions around roles- It is worth noting that research can contribute to continued stereotypical reinforcements. Ethnography has colonial origins and there is a possibility that this study will reinforce those negative stereotypes of power relationships between researcher and participant. The researcher credentials as longtime Asian resident will be enforced and the position that the researcher is learning and sharing and participant observer will be enforced. The examination of exploitation of the participants is important and the mutual respect for services rendered should be acknowledged. Incentives proffered by the researcher will be to provide daily meals from the hospital canteen for the participant and their caregiver. A further aspect of ethics for consideration is the legacy left behind by researchers for future researchers. The study will be mindful of conducting the research to appropriate ethical standards to minimise further degradation of the trust.

Hospital Identification/ dissemination ethical issues- the publication of material from this research should be mindful that the hospital context where it will be conducted could be easily identifiable. In an environment where critical feedback is rare and the culture of assessment absent, it will be important to be cognisant that a hospital and informal caregivers are not labelled as ‘bad'. This can be done through international comparisons of similar research and also in the dissemination phase within the country.

SECTION FOUR: signature

Applicant electronic signature: Dat

Unarose

9/12/201

Student applicants: please tick to confirm that you have discussed this application with your supervisor and that they are happy for the application to proceed to ethical review

Project Supervisor name (if applicable): discussed

9/12/201

Dr Amanda Bingley, Prof. Catherine

7.14 Appendix 14: Presentation of proposal in Vietnam

Health Research | Lancaster University

FAO: Hospital Director Viet Duc Hospital, Hanoi

I am writing to introduce our student Unarose Hogan studying for her PhD in Public Health in the Faculty of Health and Medicine, Lancaster University, UK. My colleague and I Professor Catherine Walshe are supervising this dissertation "Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; a focused ethnographic study". I understand she has applied to Viet Duc Hospital, Hanoi as the site to conduct her research and I would like to submit this letter in support of her application with your hopsital.

Having undergone review and approval by the ethics committee at Lancaster University, I am confident this research is well designed and has excellent potential to make a contribution to the medical literature.

We would be most grateful if you were willing to approve her application to collaborate with Viet Duc hospital. Should you have any questions or require any further clarification please do not hesitate to contact me.

Yours sincerely

Dr Amanda Bingley, BSc (Hons), PhD
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IRB Presentation to Vietnam Hospital Ethics Board

Understanding the Role of family members in Infection Prevention and Control in hospitals in low-middle income countries; A focused ethnography.

Researchers: Unarose Hogan

Supervisors: Dr. Amanda Bingley; Dr. Catherine Walsh

Introductions

- Lancaster university is ranked no.6 in the UK, it is among the best research institutes in UK.
- The Faculty of Health and Medicine's multidisciplinary research and teaching spans health research, biomedical research and medical education.
- The research team includes:

Ms. Unarose
Hogan
PhD Student

Dr. Amanda
Bingley,
Lancaster Uni

Professor
Catherine
Walshe,
Lancaster

Background

Health & Medicine | Lancaster University

Hospital Acquired Infections (HAI's) are a global health care problem.

Hospital infection control programs aim to stop HAI transmission through changing health care worker behavior.

Infection Control Programs are not designed with the realities of health systems in mind where there family member is often the one providing patient care and not the health care worker.

Understanding the role of the family member will provide information to support the development of educational programs to ensure they have adequate skills

Current Research

- In Bangladesh Islam *et. al* (2014) observed that patient caregivers were involved in a range of patient care activities from direct patient care, indirect care, psychological care, cleaning activities and that the possibility of HAI transmission from these activities was possible.

- In Cambodia Sakurai- Doi et. al (2014) observed that patient care and immediate environmental health were viewed by nurses as the responsibility of informal caregivers.

- In Bangladesh Hadley et. al (2007) found informal caregivers were assigned to undertake undesirable patient care tasks such as urinary catheter insertion and other 'hands-on' patient care.

Research Aim

- *To explore the role of family members in infection prevention and control in hospitals in low middle-income countries.*

- **Objectives:**
- To determine what patient care practices family members perform in the hospital and the associated risk for infection control of these practices.
- To determine any infection control practices family members engage in during the course of their caregiving practices.
- To explore family members perceptions of their role in infection control during the course of their caregiving practices.
- To explore healthcare workers perception of the role of the family member in infection prevention and control in the hospital.

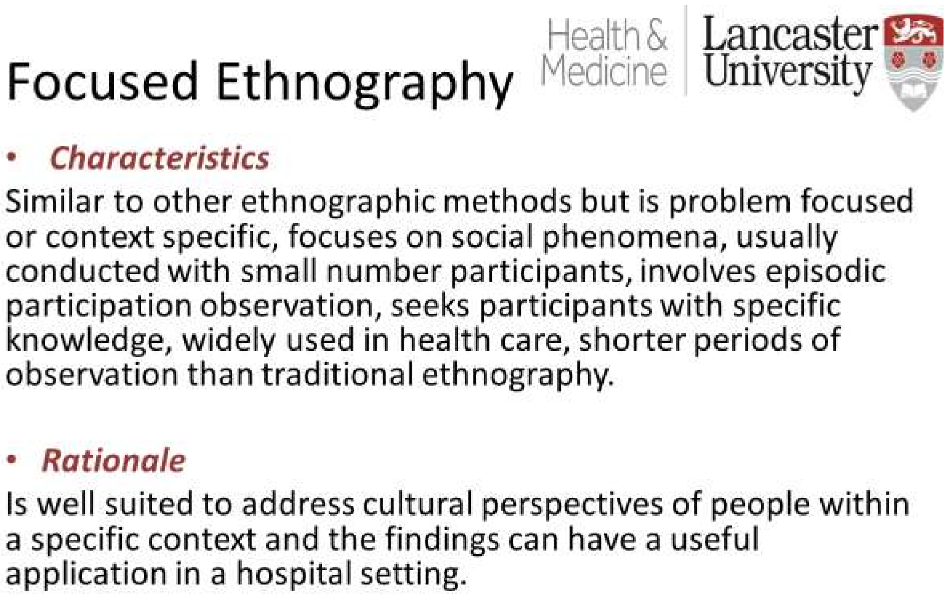
Underpinning Theory

Systems theory

- A holistic view of how individuals in an environment interact to provide a contextual understanding of behaviour.
- The health care system is an open complex system with multiple subsystems operating within the whole.
- Family members are one component part of the health system and may perform behaviours that can affect patient safety outcomes.
- Analyzing the role of the family member from the perspective of a unit within this system will aid the understanding of their role as part of the greater health system whole to situate a contextual understanding of their role.
- Strengthening one part of the system can lead to an improvement in the overall system whole and this research will underpin the analysis of the family member role against this theoretical lens.

Methods Overview

- Qualitative study design
- Focused ethnographic methodology
- Participants: 10-20 informal caregiver participants; 8-15 health care workers
- Sampling: Mixed purposive using criterion and snowballing
- Data collection: ethnographic observation & interviews
- Recruitment: posters
- Consent: fully written consent in Vietnamese
- Data Analysis: thematic



Focused Ethnography

- ***Characteristics***

Similar to other ethnographic methods but is problem focused or context specific, focuses on social phenomena, usually conducted with small number participants, involves episodic participation observation, seeks participants with specific knowledge, widely used in health care, shorter periods of observation than traditional ethnography.

- ***Rationale***

Is well suited to address cultural perspectives of people within a specific context and the findings can have a useful application in a hospital setting.

Participants

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Lancaster University

- 10-20 potential family member participants
- 8- 20 potential healthcare workers (HCW's)

	Caregivers	HCW's
Inclusion Criteria	Meet WHO definition of informal caregiver	HCW's employed for more than one year at the hospital
	Family members of patients admitted longer than 48 hours	HCW's employed in the infection control team at the hospital
Exclusion Criteria	Family members in non-inpatient settings	HCW's with less than one years experience
	Family members under 18 years old	
	Family members with any health care training in the past	

Sampling

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Lancaster University

- ***Characteristics***

A mixed purposive sampling approach using both criterion and snowball sampling.

- ***Rationale***

Purposive sampling aims to gather information-rich cases and will include seeking caregivers with a range of experiences to understand their varying perspectives and is typical in qualitative research. Criterion sampling is helpful in this study to identify and select cases that meet the predetermined criterion of importance as outlined in the inclusion and exclusion criteria. Snowball sampling will allow the identification of cases of interests from other family members and healthcare workers with similar characteristics. This approach can facilitate triangulation to ensure theoretical saturation occurs.

Recruitment

Characteristics

Under the advice of the hospital management; a contact within the hospital will help to recruit participants and also a Vietnamese speaking co-researcher to facilitate conversation with the family members and health care worker participants.

Tìm hiểu vai trò của người chăm sóc không có chuyên môn ở Việt Nam

Nội dung nghiên cứu

Đây là một nghiên cứu khảo sát về vai trò của người chăm sóc không có chuyên môn trong hoạt động chăm sóc bệnh nhân hàng ngày tại bệnh viện.

Tôi có bắt buộc phải tham gia không?

Không. Việc tham gia nghiên cứu là hoàn toàn tự nguyện; nếu bạn không đồng ý, cũng không có vấn đề gì hết. Nếu muốn tham gia nghiên cứu, xin báo với bác sĩ hoặc điều dưỡng tại khoa, hoặc nhắn vào số điện thoại, hoặc ghi tên bỏ vào hộp thư tại khoa.

Tôi sẽ được hỏi gì nếu tham gia?

Nếu tham gia, xin đăng kí bằng cách nhắn tin hoặc bỏ thư vào hộp. Bạn sẽ tiếp tục chăm sóc bệnh nhân như bình thường, và nghiên cứu viên sẽ quan sát các việc bạn làm và ghi nhận lại. Bạn sẽ tham gia một cuộc phỏng vấn và được hỏi một số ý kiến chi tiết hơi về công việc hàng ngày, cuộc phỏng vấn sẽ kéo dài khoảng 1 giờ.

Ai tiến hành nghiên cứu này?

Unarose Hogan, nghiên cứu sinh tại Đại học Lancaster, Anh Quốc.

Tôi có thể lấy thêm thông tin ở đâu?

Nếu muốn tìm hiểu thêm thông tin về nghiên cứu, bạn có thể gặp điều dưỡng tại khoa và hỏi xin một tờ thông tin, hoặc nhắn tin vào số điện thoại dưới đây.

Để biết thêm chi tiết, xin NHẮN TIN vào số 0163 3677318 với nội dung
"1" nếu bạn quan tâm và có ý định tham gia nghiên cứu
"2" nếu bạn muốn biết thêm thông tin về nghiên cứu
"3" nếu bạn có vấn đề phàn nàn về nghiên cứu

Consent

Characteristics

Participation is voluntary and participants may withdraw at any time after data collection. Written consent for observations and interview will be sought. .

CHẤP THUẬN KHÔNG THAM GIA NGHIÊN CỨU

Nghiên cứu:

Tìm hiểu vai trò của người chăm sóc không có chuyên môn trong dự phòng và kiểm soát nhiễm trùng ở bệnh viện tại các quốc gia thu nhập trung bình-thấp; nghiên cứu dân tộc học tập trung.

① Tôi đã đọc phiếu thông tin dành cho nghiên cứu nêu trên và đã có cơ hội để đặt câu hỏi. ☐

② Tôi KHÔNG MUỐN tham gia vào nghiên cứu nêu trên và xác nhận rằng anh/chị KHÔNG ĐƯỢC PHÉP sử dụng các dữ liệu đã thu thập về tôi cho nghiên cứu trên. ☐

Họ tên người tham gia ____________ Kí tên ____________ Ngày ____________

③ Tôi xác nhận đã cung cấp phiếu thông tin về nghiên cứu này cho người tham gia trên, giải thích những hoạt động trong nghiên cứu và trả lời tất cả những câu hỏi mà tôi được hỏi. ☐

Nghiên cứu viên (kí tên) ____________ Ngày ____________

Data Collection

- ***Characteristics***

Data collection will be through overt ethnographic observations and interviews. Observations will be 1-4 hours long where the researcher will be in the clinical unit and taking some notes for participants. 3 – 4 weeks of observations will occur over a 3-4 month period. Interviews will be 45 minutes long and conducted with translation at the end of the observation periods.

Rationale

Focused ethnography uses intermittent observation as its main data collection method. This is appropriate for this study where initial observations will be made and analyze and will inform the next series of observations. Interviews will be used to understand any practices observed and to investigate informal caregiver and health care worker perspectives.

Data Management

- ***Characteristics***

Field notes will be hand written and then transferred electronically into MS Word. Interviews will be recorded and transcribed and translated into English. All material will be stored on a password protected computer. All files will be stored aligned with Lancaster university policy and destroyed once the PhD thesis is submitted.

Rationale

All data will be treated with the highest sensitivity. Participants will be anonymised and not identified throughout the research. The hospital will not be identified throughout the reseach process. Legal requirement aligned to the UK's data protection act and any Vietnamese legal requirements will be strictly adhered to.

Data Analysis

Characteristics

Data analysis will be qualitative in nature and be iterative and cyclical. First step will include coding of data into broad categories and reducing this information into descriptive labels. The descriptive labels will be sorted for patterns into smaller subsets to identify codes, which show patterns of data, which are alike and unalike. Emerging patterns develop which fit the data that help to explain reoccurring relationships in the data. Data, which does not easily fit, can be identified as outliers and can be used to test the rest of the data.

Rationale

Production of thematic textual data is an appropriate method for analysis qualitative data. It is especially relevant when investigating a topic for which there is little prior knowledge and when examining peoples perception and perspectives.

Research Ethics

Characteristics

Full ethical permission from the UK research board has already been granted.

IRB approval from Than Nhan being sought today for permission to conduct the study at the hospital site.

7.15 Appendix 15: Observation written consent

Consent Form for Observations

Study Title: Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; a focused ethnographic study.

Before you consent to participating in the study we ask that you read the statements below and mark each box below if you agree. If you have any questions or queries before signing the consent form, please speak to the principal investigator, Unarose Hogan.

1 I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐

2 I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

3 I understand that any observations made will be recorded in notes by the researcher and then made into an anonymised results. ☐

4 I understand that the notes will be kept until the research project has been examined. ☐

5 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

6 I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐

7 I understand that the information from the observations of my practicewill be pooled with other participants', anonymised and may be published ☐

8 I consent to information from my observations being used in reports, conferences and training events. ☐

9 I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a:

- risk of harm to myself or others, in which case the principal investigator will/may need to share this information with his/her research supervisor. ☐

I consent to take part in the above study.

Name of Participant___________________ Signature________________ Date ____________

Name of Researcher ___________________Signature ________________Date ____________

7.16 Appendix 16: Opt-out consent

OPT-OUT CONSENT FORM

Study title:

Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; a focused ethnographic study.

1 I have read the Information sheet provided for the above study and have had the opportunity to ask questions. ☐

2 I DO NOT wish to take part in the above study and confirm that you Do NOT have permission to use data already collected about me for the above study. ☐

Name of participant	Signature of participant	Date

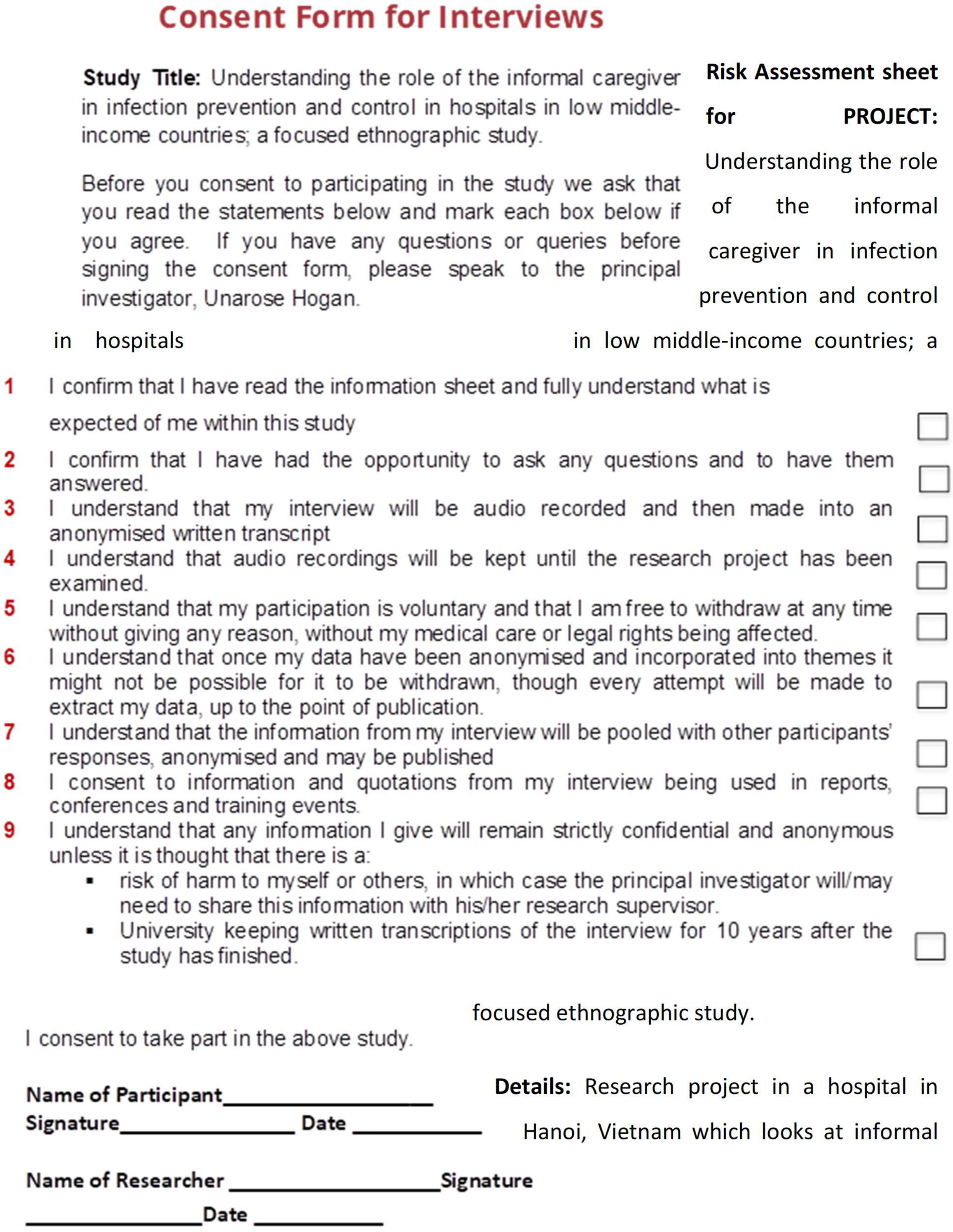
3 I confirm that I have provided the Information Sheet concerning this research project to the above participant, explained what participating involves and have answered any questions asked of me. ☐

Signature of Researcher	Date

Lancaster University

7.17 Appendix 17: Interview written consent form

7.18 Appendix 17: Researcher risk assessment



Consent Form for Interviews

Study Title: Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; a focused ethnographic study.

Before you consent to participating in the study we ask that you read the statements below and mark each box below if you agree. If you have any questions or queries before signing the consent form, please speak to the principal investigator, Unarose Hogan.

1 I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2 I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3 I understand that my interview will be audio recorded and then made into an anonymised written transcript ☐
4 I understand that audio recordings will be kept until the research project has been examined. ☐
5 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
6 I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7 I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published ☐
8 I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9 I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a:

- risk of harm to myself or others, in which case the principal investigator will/may need to share this information with his/her research supervisor.
- University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

I consent to take part in the above study.

Name of Participant__________________
Signature______________ **Date** __________

Name of Researcher __________________**Signature**
______________**Date** __________

Risk Assessment sheet for PROJECT: Understanding the role of the informal caregiver in infection prevention and control in hospitals in low middle-income countries; a focused ethnographic study.

Details: Research project in a hospital in Hanoi, Vietnam which looks at informal caregivers role in providing patient care.

Appendix 17 Researcher Risk Assessment

Activity	The Hazard	Worst likely outcome	How likely	Level of risk	Controls
Ethnographic Observations in a hospital unit	Exposure: Observations of patient care practices necessitate the researcher being in a hospital environment, which may present a risk for environmental exposure to pathogenic organisms.	Fatal	Possible	Low - Med	Choice of hospital environment will exclude infectious disease units where confirmed infectious patients in the hospitals are placed. Isolation units are also excluded where patient with known airborne or droplet transmission infections are placed and caregivers of patients in these environment will not be observed. Direct contact with patients will be avoided and it is not anticipated that any time the researcher will be in physical contact with a patient. The researcher will aim to maintain a distance of one meter or more from the patient and caregiver however it can

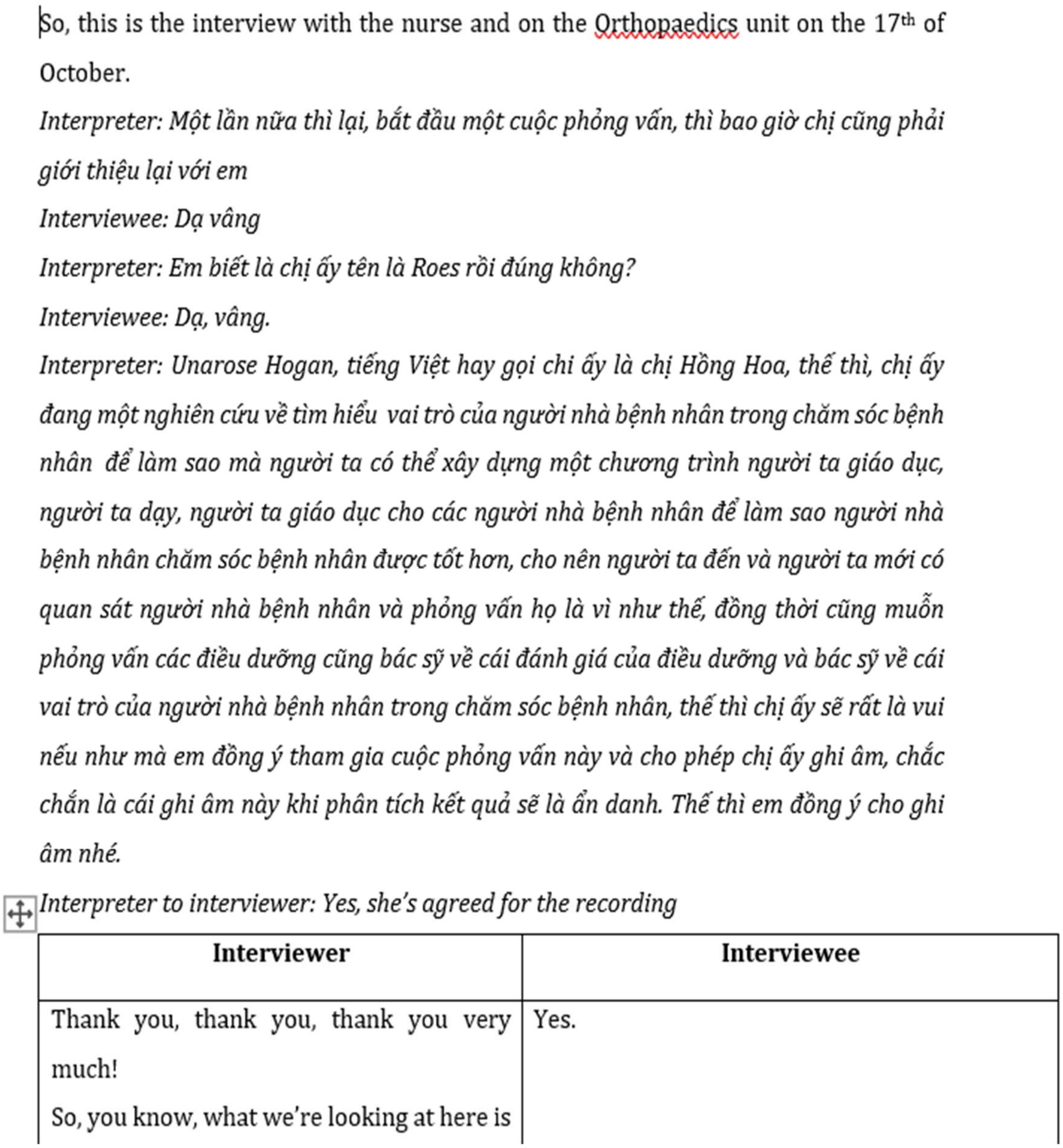
					reasonably be anticipated there may be times where this is not feasible. Should the researcher come into contact with the hospital environment standard precautions will be adhered to including hand washing or alcohol hand gel usage. Routine observations should not necessitate the use of PPE; however the researcher will maintain a supply of gloves, gowns and an N95 respirator in the event of unexpected event. Should unintended contact with blood or bodily fluids occur; immediate hygiene and blood borne precautions will be initiated. This includes handhygiene, or in the event of a mucous membrane exposure such as eye or mouth-irrigation, followed by blood testing and hospital occupational practices such as patient screening for blood borne virus

					infection and initiation of post exposure prophylaxis will occur where necessary. The researcher maintains a private health insurance which can cover all aspects of PEP as indicated. For minor accidents, falls or otherwise that may occur the researcher will carry a first aid kit. Researcher will maintain the contact numbers for the emergency department of a suitable hospital facility in Hanoi, Vietnam in the event of an unintended accident. Back up contact through the hospital INFECTION PREVENTION AND CONTROL department and also the medical translator will be maintained for any unintended accidents.

Interviews	Distress	Major effect	Possible	Low-med	Researcher; translator and interviewees should be made aware that the interviews are not intended to cause distress and should they feel uncomfortable they are welcome to stop the interview process at any stage.
Travel to and from the hospital	Danger to researcher travelling to hospital site through vehicle accident and also travelling alone occasionally at night	Major injury	Possible	med	Road traffic accidents are common in Vietnam to address this risk main routes using a reputable taxi company will be used. A back up contact in the case of emergency will be available.

Signed: Unarose Hogan, PhD Public Health, Lancaster

7.19 Appendix 19: Transcription examples



So, this is the interview with the nurse and on the Orthopaedics unit on the 17th of October.

Interpreter: Một lần nữa thì lại, bắt đầu một cuộc phỏng vấn, thì bao giờ chị cũng phải giới thiệu lại với em

Interviewee: Dạ vâng

Interpreter: Em biết là chị ấy tên là Roes rồi đúng không?

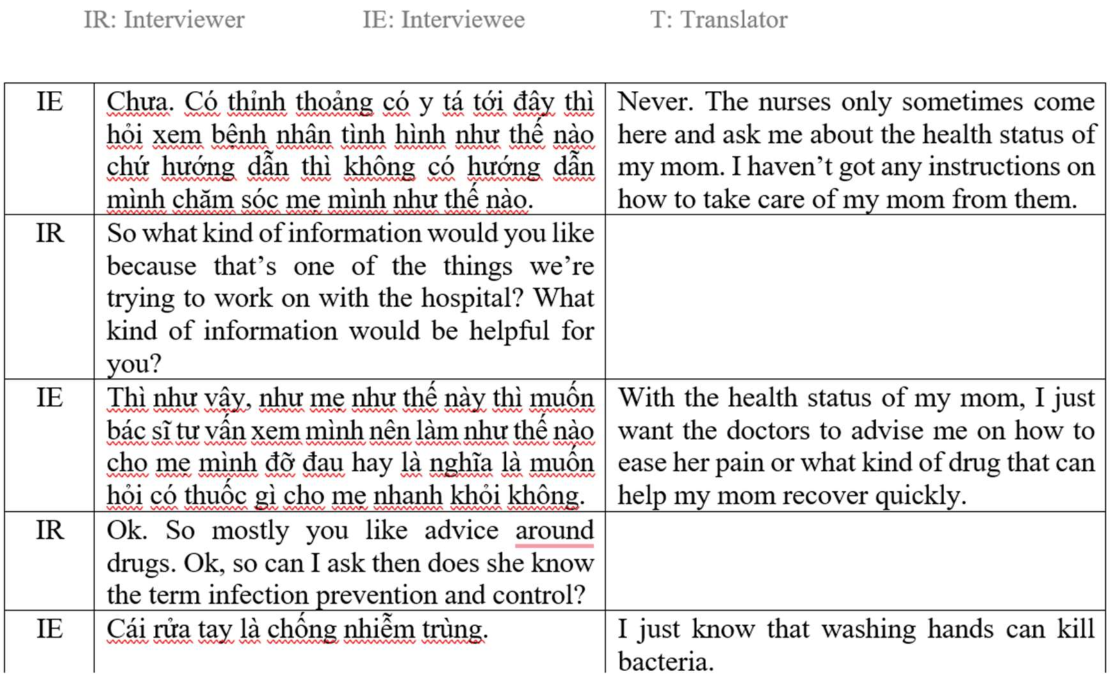
Interviewee: Dạ, vâng.

Interpreter: Unarose Hogan, tiếng Việt hay gọi chi ấy là chị Hồng Hoa, thế thì, chị ấy đang một nghiên cứu về tìm hiểu vai trò của người nhà bệnh nhân trong chăm sóc bệnh nhân để làm sao mà người ta có thể xây dựng một chương trình người ta giáo dục, người ta dạy, người ta giáo dục cho các người nhà bệnh nhân để làm sao người nhà bệnh nhân chăm sóc bệnh nhân được tốt hơn, cho nên người ta đến và người ta mới có quan sát người nhà bệnh nhân và phỏng vấn họ là vì như thế, đồng thời cũng muỗn phỏng vấn các điều dưỡng cũng bác sỹ về cái đánh giá của điều dưỡng và bác sỹ về cái vai trò của người nhà bệnh nhân trong chăm sóc bệnh nhân, thế thì chị ấy sẽ rất là vui nếu như mà em đồng ý tham gia cuộc phỏng vấn này và cho phép chị ấy ghi âm, chắc chắn là cái ghi âm này khi phân tích kết quả sẽ là ẩn danh. Thế thì em đồng ý cho ghi âm nhé.

Interpreter to interviewer: Yes, she's agreed for the recording

Interviewer	**Interviewee**
Thank you, thank you, thank you very much! So, you know, what we're looking at here is	Yes.

OK, OK. Has he been in this ward for the 4 months or in a different ward?	He experienced 3 surgeries. For the 1st surgery, it was conducted/performed at Viet-Duc hospital and after the surgery, he was transferred to Bach Mai hospital for radiology treatment, 3 months after that. And, after that he had the 2nd and 3rd surgeries at Hanoi Medical University Hospital and after the surgeries at Hanoi Medical University, the family asked them to transfer the patient here for the care and treatment but she said that after sent/transferred here, the patient has better progression.
Good. Did you ask to come to Thanh Nhan because it is closed to where you live or it has good reputation or what is the reason, exactly?	Yes, this hospital is near her house and since he was in Thanh Nhan hospital the progression is better, however, now, he has a ulcer, here, in the back and also he is in the treatment, physiological treatment, massage everyday.
OK. Well, I'm very sorry that your son is so unwell and I'll be praying for his recovery.	Now, from here upward (upper part of the body) it's good for him, and he can recognize everything.
Great!	However, from here downward (lower part of the body), everyday, they are treating for him.
Has he got, has he been paralyzed?	No, not paralyzed, but perhaps because he doesn't move for a long time so the joint is



IR: Interviewer IE: Interviewee T: Translator

IE	Chưa. Có thỉnh thoảng có y tá tới đây thì hỏi xem bệnh nhân tình hình như thế nào chứ hướng dẫn thì không có hướng dẫn mình chăm sóc mẹ mình như thế nào.	Never. The nurses only sometimes come here and ask me about the health status of my mom. I haven't got any instructions on how to take care of my mom from them.
IR	So what kind of information would you like because that's one of the things we're trying to work on with the hospital? What kind of information would be helpful for you?	
IE	Thì như vậy, như mẹ như thế này thì muốn bác sĩ tư vấn xem mình nên làm như thế nào cho mẹ mình đỡ đau hay là nghĩa là muốn hỏi có thuốc gì cho mẹ nhanh khỏi không.	With the health status of my mom, I just want the doctors to advise me on how to ease her pain or what kind of drug that can help my mom recover quickly.
IR	Ok. So mostly you like advice around drugs. Ok, so can I ask then does she know the term infection prevention and control?	
IE	Cái rửa tay là chống nhiễm trùng.	I just know that washing hands can kill bacteria.

7.20 Appendix 20 : Vietnamese list of infection control terms

Danh sách các thuật ngữ dùng trong Kiểm soát nhiễm khuẩn

Thuật ngữ	Chữ viết tắt	Tiếng Việt
Adverse event		Biến cố bất lợi
Airborne precautions		Các dự phòng lây truyền theo đường không khí
Alcohol hand sanitiser		Dung dịch rửa tay có chứa cồn
anesthesia		Gây mê
Antimicrobial resistance	AMR	Kháng kháng sinh
apron		Tạp dề
Aseptic non touch technique	ANTT	Kỹ thuật vô trùng không chạm
Aspirate		Hút
Audit		*not to be confused with surveillance Kiểm tra
Blood spill		Vết máu, vết máu tràn
Blood Stream Infection	BSI	Nhiễm trùng máu
Bodily fluids/Body fluids		Dịch cơ thể
Body secretions		Chất tiết của cơ thể
Catheter Associated urinary tract infection	CAUTI	Nhiễm trùng đường tiết niệu do đặt thông tiểu
Central sterile services department	CSSD	Khoa khử nhiễm tập trung
Cerebral spinal fluid	CSF	Dịch não tủy
Chest drain		Dẫn lưu lồng ngực
Clinical care		Chăm sóc lâm sàng
Clinical condition		Điều kiện lâm sàng
Clinical practice		Thực hành lâm sàng
Cohort		Nhóm hoặc nghiên cứu thuần tập (từ này có 2 nghĩa)
Cohorting care		Chăm sóc theo nhóm
Colonisation		Tạo khuẩn lạc, mọc khuẩn lạc
Confirmed case		Các trường hợp được chẩn đoán khẳng định
Contact precautions		Các dự phòng lây truyền do tiếp xúc
Contact tracing		Truy dấu tiếp xúc
Contagious		Truyền nhiễm (lây nhiễm)
Contamination		Nhiễm (nhiễm bẩn, nhiễm trùng)

Cross transmission		Lan truyền chéo
Decontamination		Khử nhiễm
Diagnosis	Dx	Chẩn đoán
Disease transmission		Truyền bệnh
Drip stand		Đứng nhỏ giọt
Droplet precautions		Các dự phòng lây truyền do hạt mù
Environmental contamination		Nhiễm từ môi trường
Ethnography		Dân tộc học
Exposure incident		Sự cố phơi nhiễm
Febrile		Sốt
Fecal sampling		Lấy mẫu bệnh phẩm phân
Gloves		Găng tay
Gown		Áo choàng (loại cài sau)
HAI surveillance protocol		Đề cương giám sát HAI (nhiễm trùng bệnh viện)
Handwashing		Rửa tay
Hepatitis		Viêm gan
Hospital Acquired Infection	HAI	Nhiễm trùng bệnh viện
Hospital guideline		Hướng dẫn bệnh viện *(của, cho)*
Incidence		Số mắc mới, tỷ lệ mắc mới
Incubation period		Giai đoạn ủ bệnh
Infection carrier		Người mang trùng
Infection control committee	INFECTION PREVENTION AND CONTROLC	Hội đồng kiểm soát nhiễm khuẩn
Infection outbreak		Ổ dịch nhiễm trùng
Infection Prevention & Control	INFECTION PREVENTION AND CONTROL	Dự phòng và Kiểm soát Nhiễm trùng
Intravenous	IV	Đường tĩnh mạch
Isolation		Phân lập
Laboratory		Phòng xét nghiệm/phòng thí nghiệm
Mask (N95)		Khẩu trang N95
Microorganism		Tác nhân vi sinh, tổ chức vi sinh
Methicillin resistant staphylococcus aureus	MRSA	Tụ cầu vàng kháng methicillin
Multi drug resistant organism	MDRO	Tác nhân đa kháng
Nasogastric tube	NG tube	Ống thông dạ dày
Nebuliser		Máy khí dung

Negative air flow room		Phòng áp lực âm
Occupational health		Sức khỏe nghề nghiệp
Oral fecal route		Đường phân-miệng
Oxygen cylinder		Bình ô-xi
Oxygen mask		Mặt nạ ô-xi (mặt nạ dưỡng khí)
Pathogen		Tác nhân gây bệnh
Personal protective equipment	PPE	Dụng cụ bảo hộ cá nhân
Post operative	Post op	Sau phẫu thuật
Prevalence		Số hiện nhiễm, tỷ lệ hiện nhiễm
Psychological support		Hỗ trợ tâm lý
Qualitative research		Nghiên cứu định tính
Referall (Referral?)		Chuyển tiếp (giới thiệu và chuyển bệnh nhân), tham chiếu
Reservoir		Ổ chứa
Saline		Nước muối sinh lý
Specimen culture (blood; urine; muscus)		Cấy bệnh phẩm (máu; nước tiểu; chất nhày)
Standard operating procedure	SOP	Quy trình thực hành chuẩn
Standard precautions		Các dự phòng chuẩn
Sterilisation		Vô trùng, tiệt trùng
Suppository		Thuốc đạn (dùng để đặt âm đạo, hậu môn)
Surgical site infections	SSI	Nhiễm trùng vết mổ
Surveillance		Giám sát
Susceptible		Cảm nhiễm
Systems theory		Thuyết hệ thống
Transmission based precautions		Dự phòng dựa vào con đường truyền bệnh
Vectors		Vec-tơ (trung gian truyền bệnh)
Ventilator associated pneumonia	VAP	Viêm phổi do thở máy
World Health Organization	WHO	Tổ chức Y tế Thế giới
Wound care		Chăm sóc vết thương

Glossary

Throughout this thesis, the following terms are central to the research and are clarified here for understanding:

Hospital-acquired infections: Infections occurring more than 48 hours after admission which are not present or incubating at admission (World Health Organization (WHO), 2002, 2004).

Infection prevention and control: A series of work practices performed to prevent infection transmission. Infection prevention and control is a clinical and public health speciality based on a practical, evidence-based approach that protects patients and health workers in and visitors to healthcare facilities by preventing avoidable infections, including those caused by antimicrobial-resistant pathogens acquired during the provision of healthcare services (WHO, 2020).

Informal caregivers: The term 'informal caregivers' used throughout this research aligns with the World Health Organization's definitions of 'caregivers' and 'informal assistance'. It describes any person without formal health training who is not employed by the hospital facility and is onsite in the capacity of a 'carer' or 'guardian' of a person known to them who is admitted to the facility as a patient (WHO, 2004).

Low- and middle-income countries: The World Bank groups economies into one of four categories: low-income, lower-middle-income, upper-middle-income and high-income. Gross national income per capita is the leading indicator the World Bank uses to show where a country sits in these categories. For the 2022 fiscal year, low-income economies are defined as those with a gross national income per capita, calculated using the World Bank Atlas method, of $1,045 or less. Lower-middle--income economies are those with a gross national income per capita between $1,046, and upper-middle-income economies are those with a gross national income per capita between $4,096 and $12,695; high-income economies are those with a gross national income per capita of $12,696 or more

(World Bank, 2022c). This research concerns countries in the low- and middle-income brackets.

Surveillance: surveillance is defined as the ongoing systematic collection, analysis and interpretation of health data essential to the planning, implementation and evaluation of public health practice (Thacker & Berkelman, 1988).

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