HOSPITAL AND CARE HOME NURSE PERSPECTIVES ON OPTIMISING CARE FOR PEOPLE LIVING WITH DEMENTIA WHO TRANSFER BETWEEN HOSPITALS AND CARE HOMES

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Hospital and care home nurse perspectives on optimising care for people living with dementia who transfer between hospitals and care homes

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Abstract

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Hospital and care home nurse perspectives on optimising care for people living with dementia who transfer between hospitals and care homes.

Keywords: Nurses, transitional care, hospital discharge, older people, nursing homes.

Background: Transitions out of hospital result in poor outcomes for older people. Research investigating transitions for care home residents living with dementia is limited, even though such residents often have multi-morbidities and frequently use hospital services. Nurses are key care providers. Yet their perspectives on optimising care for people living with dementia transferring back to their care home remains under explored.

Aims: This qualitative descriptive study explores hospital and care home nurses' perspectives on how they optimise care for people living with dementia who transfer from hospital back to their care home, and the alignment of this care with best practice.

Methods: Thirty-three nurses participated in either semi structured interviews or focus groups. Data were analysed using qualitative content analysis.

Results: Nurses described four roles: 1) exchanging information, 2) assessing and meeting needs, 3) working with families and 4) checking and organising medication. They described care home residents with dementia as having distinct needs and variation in how they provided care. Nurses described interdependent roles, but care home nurses were often excluded from involvement in planning resident's care on return and were not fully recognised as members of wider healthcare teams. Facilitators for optimising care include: nurses understanding the principles of dementia care, nurse leadership and autonomy, having positive relationships between hospital and care home nurses and opportunities for joint working. The care practices nurses described broadly aligned with best practice.

Implications: Hospital and care home nurses require joint working opportunities to understand their roles and build relationships. Care home nurses' status needs to be addressed with action to support their integration into the wider healthcare system.

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Chapter One: Introduction and Background

Improving care for people living with dementia is a key ambition in the United Kingdom (UK) and internationally. This includes improving the quality of care when people living with dementia transition from hospital to other care settings, such as their own home or care home. This transition is notoriously difficult. It is often described in the UK as ‘ineffective’ or ‘delayed’ hospital discharge leading to untoward outcomes for frail older people, including people living with dementia. In this first chapter I will describe care homes, their residents and the problem of ineffective discharge from multiple perspectives. I will locate this problem of ineffective hospital discharge in the context of government policy in three inter-related areas: 1) improving care for people living with dementia, 2) the need for integrated health and social care and 3) the role of nurses in dementia care. I then go on to present research evidence of effective ways to support older people and people living with dementia as they move from hospital back to their own home or care home. I argue we have a limited evidence base to guide improvements in care of people living with dementia as they transition back to their care home from hospital. This is despite the significant proportion of care home residents who live with dementia and co-morbidities, their relative frequent use of hospital services and increased vulnerability at times of transition. I therefore argue there is a need to understand more about the experiences and outcomes of care for people living with dementia, who are discharged from hospital to care homes, from all stakeholders involved in this transition.

1.1. Terminology used regarding people living with dementia

This thesis addresses care of people living with dementia moving from hospital back to their care home. I will use the term ‘people’ or ‘person’ living with dementia as much as possible throughout the thesis. However, when the context is mostly care home resident related, I will use the term ‘resident living with dementia’.

1.2. Care homes and care home residents

In this section I will define what I mean by care home, describe care home residents, the nature and extent of their co-morbidities and their likelihood of them being admitted to hospital. I will argue that given residents living with dementia frequently live with co-morbidities we need to ensure their safety and provide optimal care when they transition back to their care home from a hospital stay.

1.2.1. Definition of care homes

A ‘care home’ is a broad category referring to facilities that provide long-term care (Moriarty et al., 2019). Internationally terminology to describe care homes varies. The World Health Organisation (WHO, 2004) defines residential care facilities as a place where older people live and receive twenty-four-hour support with personal services but do not require twenty-four-hour support from a health care professional. Nursing homes are defined as high dependency care facilities providing nursing and rehabilitation services (Andrews et al., 2004). A European report identifies that most European countries differentiate between these two models of long-term care and a range of terminology is used for example ‘care homes’ ‘residential care’ and ‘nursing homes’ (Eurofound, 2017).

Australia also divides care into these higher and lower level care needs and uses the term ‘Aged care facilities’ (Australian Government, 2019). In the United States (US), similar provision is noted but their higher dependency provision is a little more complex with ‘Skilled nursing facilities’ or nursing homes providing short and long-term nursing care. Although these terms are often used interchangeably there are distinct differences. Skilled nursing facilities provide a range of medical and nursing care as well as therapy services and are most commonly used for short and medium-term care, following a hospital admission. Skilled nursing can be provided in any location and registered nurses are available twenty-four-hours a day. Some skilled nursing facilities are located within nursing homes. In contrast, nursing homes provide long-term care and are staffed with nurses, social workers and health care aides but are not required to have a qualified nurse on duty twenty-four hours a day (Pratt, 2019). Many US research studies on long-term care are conducted in skilled nursing facilities.

1.2.2. Care homes in England

In England, care homes are split into two groups, care homes ‘with nursing’ sometimes referred to as nursing homes and care homes ‘without nursing’, referred to as residential care homes. Both categories provide twenty-four-hour personal care and support. Care homes with nursing also provide care from a registered nurse (Moriarty et al., 2019), however most of the direct personal care is provided by trained care support staff (Schreuders et al., 2020).

The residential care and care home landscape is complex. This is partly due to the many changes in residential care and care home provision which have occurred over the past four decades. During the 1980’s and 1990’s the National Health Service (NHS) changed the way they provided care for people living with mental health problems. The earlier 1962 Hospital Plan announced a programme of deinstitutionalisation which involved the closure of large mental health hospitals whilst further health policies (Department of Health and Social Security,1975) led to the development of new models of care in the community (Turner et al., 2015). Care for people living with dementia was largely transferred to the growing independent care home sector (Gulbert et al., 2014). This meant that most people living with dementia who could not have their needs met at home were cared for by the residential care home sector workforce. Specialist mental health workers, which included mental health nurses, were previously the main providers of long-term dementia care. A recent survey confirmed that only a minority of Mental Health NHS Trusts, provide any long-term continuing care for older people with mental health problems (Jenkinson and Howard, 2016).

The Department of Health (DOH) continued with a policy of reducing reliance on hospital-based services and over recent decades the NHS has reduced the number of beds for older people who live with complex medical care needs, such as those in community-based hospitals (Ewbank et al., 2020). Such policies initially saw a significant increase in the numbers of residential care and nursing homes to meet the needs of older people requiring long-term health care, however, rising costs of meeting care standards and the ability to adequately staff care homes resulted in several care home closures

(Dudman, 2007). The policy thrust remains that of assisting people to stay in the community which has also been attributed to a reduction of residential and nursing home care beds (DoH, 2019, CQC, 2019). Nevertheless, a significant proportion of older people have their needs met within the residential and nursing home sector. The Competition and Markets Authority (CMA) report states there are around 410,000 residential and nursing care places in approximately 11,300 care homes in the UK, just over 40% of these are in registered nursing homes (CMA, 2017).

According to an Alzheimer’s Society report, there are approximately 280,000 people with dementia living in care homes (Alzheimer’s Society, 2016) and many are experiencing the latter stages of the condition which requires high levels of support to meet their daily needs and preferences (NHS England and NHS Improvement 2020). A large proportion of older people with dementia living in care homes are therefore cared for by a social care workforce without supervision from registered nurses. However, some residential and nursing homes are registered to provide dementia care meaning they provide care to those requiring specialist support.

Older people including those with dementia who live in residential care settings receive medical and nursing services from their GP and community nursing services (Cook et al., 2016). If older people require more nursing support, they can have a care needs assessment to determine if they meet the eligibility criteria for continuing healthcare or funded nursing care (DoH, 2018). This assessment, known as the assessment for NHS continuing care and NHS funded nursing care, is complex. Those who are eligible are deemed to meet the criteria for having a ‘primary healthcare need’ and is not dependent on diagnosis but on the intensity, complexity and unpredictability of healthcare needs (Lee and Hayes, 2019). There has been much debate regarding variability in the application of this assessment criteria (Thompson et al. 2016). Although very few studies have been conducted in this area (Lee and Hayes, 2019) there are examples of many people with dementia with a high level of need living in residential care homes but who are not assessed as eligible for NHS funded nursing care (Alzheimer’s Society 2017).

Studies of health care staff who regularly visit care home residents and those that work in them have noted that the dependency of care home residents has risen sharply over the last two decades. There is recognition that staff in residential care homes are caring for older people who would previously have been residing in nursing homes and care home nurses are caring for individuals who would have historically received care in NHS long-term care provision (Goodman et al., 2003, Royal College of Nursing, 2010, Robbins et al., 2013). It has been suggested that distinguishing between residential and nursing care is often difficult (Lievesley et al., 2012). In their study of the health status of care home residents Gordon et al. (2014) found profound dependency in residents within both types of care home. The previously referenced variability in the assessment for nursing needs may have resulted in the blurring of these boundaries.

All care homes are regulated in England by the Care Quality Commission (CQC). They have reported that care provided by care homes is of variable quality (CQC, 2019). The variation in how care homes are funded and operated may be an influencing factor as they can range from large corporate businesses to small individually owned care homes, some are operated by the charitable sector and a small number are operated by local councils (Grant-Thornton, 2018). How they provide care when a care home resident moves between care settings, such as hospitals, is also likely to vary (CQC, 2014).

The term ‘care home’ in this thesis refers to care homes with nursing. Care homes without nursing will be referred to as residential care homes.

1.2.3. Care home residents, co-morbidities and hospitalisation

About two thirds of care home residents live with dementia (Prince et al., 2016) and many of these live with co-morbidities. As identified in section 1.2.2, the acuity of care needs for people living in care homes is rising (Lievesley et al., 2011). A quality longitudinal UK study by Gordon et al., (2014) which investigated health care status of both residential and nursing home residents found high levels of dependency, multimorbidity and frailty in both populations. There is limited information about the use of hospitals by residential care and care home residents in the UK, but one study suggested that residential and care home residents experienced 40-50% more emergency admissions than the rest of the population over the age of seventy-five years (Smith et al., 2015). This figure may in fact be lower as there is now a drive to provide new models of enhanced health care in residential and care homes to reduce avoidable admissions to hospital (NHS England, 2016).

People living with dementia experience more frequent care transitions than people without dementia (Callahan et al., 2015). Dementia is often accompanied by co-morbidities (Schubert et al., 2006), diabetes and stroke being particularly common (Bunn et al., 2014). It is therefore not surprising that people living with dementia are high users of hospital services (Phelan et al., 2012). A meta-analysis of thirty-four studies which investigated hospital admission rates, causes and potential risk factors for hospital admission was undertaken by Shepherd, et al., (2019). Using the gold standard Cochrane's grading approach to assess evidence they concluded there were high levels of hospitalisation for people living with dementia compared to those without. The Alzheimer's Society (2016) have also reported UK bed occupancy of people living with dementia can be as high as 25% at any one time. A scoping review of the evidence for the World Alzheimer's report (2016) which reports on the quality and costs of health care for people living with dementia found the most common reasons for hospital admission are injuries sustained from accidents and falls, urinary tract and respiratory infections and exacerbations of other chronic health problems. Though some of these admissions may be avoidable, many are not unless there is greater investment and response from community-based services (Prince et al., 2016).

In summary, there is substantial evidence that care home residents frequently live with both dementia and comorbidities. This results in their relatively frequent admission to hospital from which, on discharge, they return to their care home. Ensuring optimal care and resident safety during this transition is essential, and the focus of this thesis.

1.3. The problem of ineffective hospital discharge

In this section I will describe the problem of ineffective discharge of people living with dementia from hospitals to care homes. First, I will describe the evidence we have about the extent of ineffective hospital discharge. Second, I will outline the potential causes of ineffective hospital discharge. Third, I describe the relatively limited evidence we have about the circumstances for care home residents who transfer back to their care homes, particularly care home residents living with dementia. The detail I now present is a combination of data from UK non-peer-reviewed reports and international evidence.

1.3.1. Extent of the problem of ineffective discharge

A report entitled 'Cracks in the pathway' by the CQC (2014) was one of the first to identify issues of poor care when people living with dementia move between hospitals and care home settings. Although some good practice was reported, overall analysis suggested quality of care was inconsistent. They reported poor or variable quality care in: assessment of care home residents' needs, sharing of patient information between settings, people living with dementia and families not involved in decisions about their care and how care was delivered. They emphasised transitions between care settings needed to improve.

Timing of hospital discharge can be poor. Analysis from a survey conducted in 2015 by the Alzheimer's Society for their 'Fix Dementia Care Campaign' identified several issues. They found almost 5,000 people living with dementia from 68 National Health Healthcare (NHS) Trusts were discharged between 11pm and 6am, often with inadequate preparation and information. Furthermore, the survey identified that delayed discharges, readmissions, and moving to a care home for the first time after a hospital admission were common in the worst performing hospitals (Alzheimer's Society, 2016). Although it has strengths, this survey did not report discharge destination and so destination may have been a mix of own home and care homes. There are some methodological weaknesses in the survey. For example, some samples were small and in some cases were self-selecting. Just over half of NHS Hospital Trusts responded to the request for information.

Nevertheless, this exploratory work highlighted some poor and variable dementia care practice for those receiving acute hospital care.

Several reports of the perspectives of older people and nursing staff identify poor experiences of hospital discharge for older people. For example, Healthwatch (2015) surveyed a sample of older people and other vulnerable groups about their experience of hospital discharge. Although some positive experiences were reported, inconsistent quality of services were also raised. The main causes of unsatisfactory experiences of hospital discharge were attributed to the breakdown of communication between hospital and community care providers and the lack of involvement of older people in making decisions about their own care. However, it is important to remember that Healthwatch are tasked with representing public views on health services and as such this may mean more negative than positive experiences were reported. Furthermore, although this report did not focus specifically on the needs of people living with dementia but as the sample included a large proportion of older people it is likely that the experiences of people living with dementia were represented.

In 2015, the Queens Nursing Institute (QNI) was commissioned by the Department of Health (DoH) to conduct a study to identify nurses' perspectives of the barriers and challenges of providing effective discharge from hospital to home. Using a mixed method approach, with focus groups and a survey of over 1,000 nurses, their report focuses on nurse perceptions of hospital and community nursing. The study highlighted models of best practice when people move from hospital to home within the UK but acknowledged these are not widespread. Significant challenges in communication and coordination between hospital and community nursing which result in unsatisfactory care provision were reported (Pellett, 2016). This report was not dementia care specific but did focus on the complex needs of older people and hospital discharge. Given the high proportion of people living with dementia and co-morbidities, it is likely their care needs met their criteria for complexity.

Similarly, a National Audit Office report (2016) about discharging older patients from hospital concluded that despite national guidance (National Institute for Health and Social Care Excellence, 2015), hospital discharge frequently remains uncoordinated. The report identified failings in information sharing, unclear accountability and misalignment of financial incentives across systems, all of which contributed to poorly executed hospital discharge.

1.3.2. The reasons for ineffective discharge

The potential reasons for ineffective discharge are multiple. Despite many NHS Hospital Trusts having discharge procedures and protocols, the National Audit Office (NAO) report (2016) found these were not always adhered to. The evaluation conducted by the NAO was based on evidence from multiple methods of data which adds to its credibility. The audit included reviewing documents relating to policy and good practice, stakeholder interviews, studies of a sample of six health and social care systems, surveys with health and social care staff and analysing hospital data activity. From the sites selected for the case study they identified for their audit; practitioners found it difficult to keep up to date with knowledge of the local services available to people upon discharge. Moreover, lack of training left clinical staff feeling ill equipped for liaising with families during discharge planning. Concerns over bed capacity in care homes and the high rate of staff nurse vacancies added further pressure on this care pathway.

Pressures on the care system which impact on discharge are well known. Research by Connolly et al. (2009) found that health care staff often felt significant pressure to discharge patients, and more recently the CQC recognised there was an increase in acute care occupancy (CQC, 2019). This increase is likely to impact on discharge pathways out of hospital.

1.3.3. Unique issues for transitions from hospital to care homes

Many of the UK reports cited above identify issues with hospital discharge in general and are not specifically focussed on transitions out of hospital to care homes. In the US, transitions between hospitals and care homes or skilled nursing facilities for older people have been highlighted as a cause for concern (LaMantia,et al., 2010, Toles et al., 2016; King et al., 2013; Shah et al., 2010; Caruso et al., 2014). Research studies as opposed to the previous cited UK reports vary in design and quality but are wide ranging and include a systematic literature review (LaMantia, et al., 2010,), a multiple case study using observations, interviews and document review (Toles, et al., 2016), a qualitative study conducting focus groups and in depth interviews (King et al., 2013), a mailed survey (Shah, et al., 2010) and a retrospective cohort study (Caruso, et al., 2014).

These studies all found care can be inconsistent and components of care that are lacking include:

- patient and family engagement in planning for the transfer (Toles et al., 2016; King et al., 2013),
- timely prepared transfers (Shah et al., 2010; King et al., 2013),
- follow up of clinical recommendations (Caruso et al., 2014),
- communication about health and medication between settings, resulting in pharmacy errors (LaMantia, et al., 2010; King et al., 2013; Caruso et al., 2014).

A literature review found these can all lead to frequent hospital readmissions (Yoo et al., 2015). A study investigating hospital readmission rates identified these rates were considerably higher in care home residents to that of people readmitted from their own home. Additionally, they found that dementia was associated with greater risk of hospital readmission from care homes. These readmissions occurred within two weeks of discharge (Bogaisky and Dezieck, 2015). A weakness with this study is that their sample was drawn from one hospital system which limits generalisability.

The US studies cited above did not focus specifically on care for people living with dementia and used a limited range of care homes in their samples, there were differences in ownership which may have influenced training and competency of staff and impact on transitional care delivered. Other limitations noted were the survey (Shah et al., 2010) which had a low response rate from nursing home administrators, who are not directly involved in providing care. Some samples were small. For example, in the

Caruso et al., (2014) study although they state that their sample was from just one site, they did use a randomised method of selection and their findings of follow up recommendations were consistent with other studies.

Despite some limitations these US studies provide evidence that care provided when a person moves between hospital to care homes or similar facilities in the US is sub-optimal and requires improvement. Given that hospital admission and transitions are distressing for people living with dementia, the increased risk of readmission to hospital is of concern.

There is little comparable evidence about the provision of care at transition from hospitals to care homes in the UK, although studies conducted in Scotland and Wales concluded that decisions to move to a care home often take place when the person is in hospital and these decisions can be difficult for those involved (Rhynas et al., 2018; Singh, et al., 2018). Furthermore, Singh et al. (2018) found the proportion of people living with dementia who died in hospital within three days of hospital admission from a care home was significantly higher compared to those admitted from their own home. Although these two studies were small and were reliant on review of medical and nursing records which may not always be accurately completed or fully represent all aspects of individual cases, they nevertheless identify that hospital to care home transitions for people living with dementia can be both challenging and high risk.

To summarise, we have known for some time that discharge processes are often ineffective, causing unnecessary distress and poor health outcomes for older people, as well as frustration for nursing staff. These problems have been well documented in a range of national reports and include: transfer at inappropriate times of the day, little forewarning of imminent discharge, poor communication and involvement of the person and their family in discharge planning. Reasons for this failure have been identified including: significant demand in the acute care system leaving staff feeling pressured to discharge patients quickly, a lack of staff training and failure to follow protocols and procedures. The few empirical studies that have investigated care provided, at transition between hospital and care homes were conducted in the US, (LaMantia et al., 2010, Toles et al., 2016; King et al., 2013; Shah et al., 2010; Caruso et al., 2014).although vary in quality, they additionally found inadequacies in care provided. As studies did not focus on the particular needs of people living with dementia we do not know if there are additional specific concerns for this client group.

There is, therefore, a need to focus effort on understanding more about how to ensure optimal care provided to people living with dementia who move between hospital and care home settings. Given the apparent lack of research evidence in the UK about care provided when a person living with dementia transitions between hospital and care home settings, there is a need for this proposed research to be undertaken in the UK.

1.4. Policy and national guidance

In this section I provide an overview of key policy developments in three inter-related areas including: care of people living with dementia, integrated health and social care, and the role of nurses in dementia care. I first describe English contemporary policy in care for people living with dementia. I will argue that a focus on improving care for people living with dementia who move between care settings is recent and relatively under-developed. I then go onto describe the various Department of Health initiatives around integrated working between health and social care. I demonstrate that this ambition is yet to be realised. I end the section by describing the increasing policy importance being given to the role of nurses in ensuring optimal dementia care.

1.4.1. Care for people living with dementia

Since the publication of *'Living well with dementia'* the first dementia strategy for England in 2009 there has been a sustained government interest in dementia care. This document set out a five-year framework with three key aims: to improve knowledge and understanding of dementia across society and the health and social care workforce, to improve recognition and diagnosis of dementia and to develop service provision (DoH, 2009). It made no explicit mention of care at transition or hospital discharge.

The *Prime Minister's Challenge on Dementia* was published in 2012. The purpose was to move forward the agenda published in the national strategy three years previously. It focused on three key areas: driving improvements in care and services, developing dementia-friendly communities and better research. While it introduced financial incentives to hospitals to provide better hospital care and highlighted improvements to be made in care homes (DoH, 2012), care provided at transition between these two environments was not mentioned.

In 2015, The *Prime Minister's Challenge on Dementia 2020* was published identifying an additional programme of work. In relation to hospital and care home provision, it drew on the findings from the '*Cracks in the pathway'* report (CQC, 2014) which demonstrated that both hospitals and care homes need to improve provision of comprehensive assessments to better meet the needs of people living with dementia. This most recent English policy document for dementia supported initiatives to reduce avoidable admissions to hospitals from care homes. It also encouraged care homes to engage and participate in dementia care research to improve the experiences of residents living with dementia.

In relation to hospital care there have been several recent initiatives to drive forward improvements in hospital care of people living with dementia. NHS Hospital Trusts have engaged in dementia care planning and identification schemes which aim to identify people living with dementia or delirium and provide a tool to support the provision of individualised care while in hospital. *The Butterfly scheme* (Williams, 2011) and the *'This is Me'* tool (Alzheimer's Society, 2020) are two examples which are used.

NHS England has commissioned an annual national audit of hospital dementia care. Since 2015, the audit of care standards has identified some improvement in discharge practice. However, during the last reporting period in 2018-2019 it highlighted that particular challenges remain. It identified that consultation of people living with dementia and those who care for them in discharge planning still requires improvement. The audit reported issues with preparing for hospital discharge stating almost three-quarters of people were given less than twenty-four hour's notice of leaving hospital. It also identified that more than half of discharge correspondence did not record behavioural and psychological symptoms which were present during admission (Royal College of Psychiatrists, 2019). This has potential significant impact on providing follow up care. For example, care home nurses need time to prepare adequately to meet and respond to symptoms.

This sustained strategic direction by the Department of Health has meant that improving dementia care remains a national priority. Additionally, The *Prime Minister's Challenge on Dementia 2020* acknowledges that hospitals and care homes are part of a care system that people living with dementia access. As well as focusing on improving care in these two settings it argues the need for an integrated approach between health and social care. Furthermore, it emphasises there is a role for research in achieving service improvement in these settings. An updated report on progress of the *Challenge* is due in 2020. It is notable that relatively limited policy attention has been paid to optimising transitions for people living with dementia to what is arguably a relatively common occurrence.

1.4.2. Integrated health and social care

Providing care between hospital and care homes requires health and social care to work together. Developing integrated working is known to be challenging. For several years there has been recognition that an integrated approach towards the delivery of care facilitates people living with dementia receiving good outcomes of care. The Department of Health in England sets out a framework of principles for system-wide action. This includes "developing coordinated health and social care systems by building care structures around patients with shared accountability across system boundaries" (DoH, 2014:5). This need for health and social care to work together when people living with dementia transfer between care settings is now mentioned in the National Institute of Health and Social Care Excellence (NICE) updated guideline on Dementia (NICE, 2018). The recommendations highlight risks associated with hospital admission and the need for care settings to share information to enable continuity and consistency in care.

Concerns about continuity of care and discharge processes relating to older people have occurred for over two decades. To address these challenges there have been several recommendations and two changes in legislation relating to hospital discharge. In recognition of the numbers of people who experienced delayed hospital discharge due to the failure to coordinate community care services, an act of parliament known as the Delayed Discharges Act 2003 was passed (DoH, 2003a). This Act introduced financial reimbursements as a mechanism to facilitate integrated working between health and social care (Baumann et al., 2007). In the same year, the Department of Health published a refreshed version of their 'Discharge Planning Workbook' to reflect the changes presented in the Delayed Discharges Act 2003 (DoH, 2003b). In 2010 the Department of Health published another good practice hospital discharge guide entitled '*Ready to go'* outlining key principles and practice recommendations for ensuring timely and safe transitions from hospital. These included planning for discharge or transfer on admission, involving patients and family carers in all aspects of discharge planning, enabling a personalised approach, reviewing clinical management and discharge plans daily. It also highlighted the role of nurses in becoming more involved in decisions about discharge and transfers of care (DoH, 2010).

Legislation passed in 2012 changed structures of how health and social care is commissioned and delivered. This act of parliament, the Health and Social Care Act (2012) placed an emphasis on health and social care working together and to continue to tackle the problem of delayed discharge (DoH, 2014b).

Despite the many attempts to improve hospital discharge it was not until 2015 that the first national guideline entitled '*Transitions between inpatient hospital settings and community or care home settings for adults with social care needs*' was published (NICE, 2015). Although this was not specifically aimed at people living with dementia, the requirement for such guidance is an indicator of the continued concern about variable care when a person is discharged from hospital to another care setting. The recommendations were developed following a quality appraisal of the existing evidence of effective care interventions. The key principles within the guideline centre on:

- better integrated working,
- person centred care,
- identifying those most at risk during the transition and providing support,
- involving families in discussions.

This guidance (NICE, 2015) recommends that hospitals consider creating a series of changes: a specialist /geriatrician led ward, a focus on multi-disciplinary comprehensive assessment of people with complex needs at admission and a single health or social care practitioner responsible for coordinating the discharge. It recommends discharge planning commencing as soon as possible after admission. There is an emphasis on providing continuity and avoiding decision-making about long-term care during a crisis. It recommends follow up by community professionals post discharge. It has not gone without criticism and a year after the guidance was published the National Audit Office report entitled '*Discharging older patients from hospitals*' considered that the evidence base for all the interventions recommended in this guidance was not always clear (NOA, 2016: 23). Nevertheless, these recommendations demonstrated a need to improve the provision and coordination of not just discharge planning and also to ensure continuity of care when an individual leaves hospital to another setting.

The NHS continues to review hospital discharge and care provided at transition to other settings. The NHS England website has dedicated pages on improving hospital discharge highlighting good practice guides, initiatives, schemes and suggested models of care for NHS Trusts and practitioners (NHS England, no date). One such scheme '*The red bag scheme'* was recently introduced to standardise the exchange of patient related information between hospitals and care homes. In this scheme the red bag is prepared by care home nurses and is sent in with the resident with the aim of increasing communication between settings (NHS England, 2018).

To summarise, while the Department of Health has led several initiatives including provision of national guidance and legislation to address the problem of ineffective discharge and care at transition (DoH, 2003; DoH, 2010; DoH, 2014; NICE, 2015; NICE, 2018), this continued revision indicates a history of failed attempts to completely solve it. Integrated working between health and social care remains inconsistent and a challenge for many English health care systems. The persistence of these challenges for care homes has been well documented in the recent COVID-19 crisis.

1.4.3. Role of nurses in dementia care

Nurses work in both health and social care settings. It is estimated over 300,000 nurses work in the NHS (Kings Fund, 2019) and around 41,000 nurses work in social care (Skills for Health, 2019). The Department of Health in England has shown significant interest in the contribution that nurses can make to people affected by dementia. In 2016, a vision and strategy for nursing in dementia care was published (DoH, 2016). This was a refreshed strategy originally published earlier (DoH, 2013).

The most recent strategy states that all nurses regardless of responsibility and of which part of the register they belong to, will need to be dementia aware, understanding the person’s unique needs and promoting a ‘dementia friendly’ environment. This phrase means to promote the physical and social environment to be inclusive of people living with dementia (Handley et al., 2017). The strategy (DoH, 2016: 9) defines the nursing role as an “interpersonal and social model of care” recognising it will be varied in action and intensity and will take place in a variety of settings. It sets out a five-phase framework of dementia from when the person first starts to notice they may have a problem right through to end of life care, presenting the critical aspects of the nurses’ role within each phase.

This strategy demonstrates that nurses have crucial roles in providing all aspects of dementia care, including providing care in all care settings. This includes delivering care to those living in health and social care environments such as care homes and when a person moves between settings.

In summary, during the last decade the Department of Health has recognised dementia care is an important health and social care priority. I have demonstrated that ineffective hospital discharge and continuity of care during transition is a significant challenge for health and social care systems in England. These problems persist despite policy intervention and national guidance. The improvement initiatives for health and social care when a person transitions out of hospital is recent and still in its early stages of implementation. The requirement for health and social care systems to work together is viewed as essential to improve care, but this too is inconsistent and challenging.

The Department of Health has also emphasised the key role of nurses in ensuring quality of care, regardless of setting where a person with dementia lives. There is now a compelling argument to explore nurse perspectives of providing care for people living with dementia who move between hospitals and care settings. This would potentially help us develop a deeper understanding of the issues involved to make recommendations as nurses are central to designing and delivering on any service improvements.

1.5. Possible solutions to the problem: Transitional care

In this section I introduce the concept of transitional care, providing a definition. I then present research evidence on effective transitional care interventions and argue that the transitional care for people living with dementia is largely unexplored.

1.5.1. Definition of transitional care

Transitional care is a key term in this thesis. Internationally, different terminology is used to refer to the care provided when a person transfers out of hospital back to the community. The term ‘transitional care’ emerged in the US in the 1980’s (Naylor, 2000). It refers to a broad range of activities. These include proactive, collaborative planning, service identification, and follow-up action delivered to ensure continuity of healthcare to improve patient outcomes when people move between levels or locations of care, most notably from the hospital to the community (Coleman et al., 2003; Naylor et al., 2011). Both Coleman and Naylor are well known transitional care researchers in the US and have developed successful transitional care interventions following robust randomised clinical trials (Naylor, 1999, Coleman, 2006). The term 'transitional care' was not used in the UK until relatively recently. As described in sections 1.3 and 1.4. the Department of Health in England has focussed a great deal of effort on improving hospital discharge processes and associated planning. However, there is now recognition that hospital discharge planning is only one element of transitional care (Coleman, 2003; Naylor et al., 2012; Burke et al., 2013). Holland and Harris (2007) reviewed hospital discharge planning terminology in the literature with the aim of defining key concepts. They noted that discharge planning was usually defined by time; specifically, the length of hospital stay from admission to the day of discharge. This might suggest that if the UK has been narrowly focussed on discharge planning with insufficient attention paid to other aspects of transitional care, this may be a contributory factor to the long-standing challenges in executing effective hospital discharge. However, other authors advocate a wider approach saying that hospital discharge is not an 'end point'. In their ethnographic study of hospital discharge Waring et al. (2014) stated hospital discharge also encompasses the coordination of 'follow up care' in the community. They identified that 'hospital discharge activities' take place across a transition pathway, starting at admission, while the person is in hospital, on the day of discharge and after discharge. Although the study of Waring et al. (2014) only centred on two UK hospital sites, they were varied in population demographics, and size. The study was comprehensive and combined over 180 hours of observation of discharge processes, used focused patient tracking across patient journeys and included 169 qualitative interviews with staff from health, social care and voluntary organisations. To acknowledge the full range of actions required for effective hospital discharge, including the continuity of care delivered when a person leaves hospital, I am using the term 'transitional care' throughout the remainder of this thesis to describe such care.

1.5.2. Research evidence on effective transitional care interventions

Most of the research on transitional care has taken place in the US and has studied the transition from hospital to home for older people, omitting a focus on people living with dementia. Two studies from the US have identified critical elements of effective transitional care (Burke et al., 2013; Naylor et al., 2017). Burke et al. (2013) identified ten domains of transitional care which they describe as structural supports of a bridge that patients cross when transferring from one environment to another. They purport that any missing elements weakens the bridge and can result in negative experience of transitional care. These ten domains are:

- discharge planning,
- complete communication of information,
- availability, timeliness, clarity, and organisation of information,
- medication safety,
- educating patients and promoting self-management,
- enlisting help of social and community supports,
- advance care planning,
- coordinating care among team members,
- monitoring and managing symptoms after discharge,
- follow-up with outpatient providers, (Burke et al., 2103: 103).

Burke et al. (2013) developed this framework based on Naylor's work on safe transitions (Naylor, 2000). Naylor is known for work in developing the Transitional Care Model (Naylor et al., 1999; 2004; 2014). Naylor et al. (2017) also led work on identifying critical components of transitional care and how they relate to patient's needs. Following a robust review of the evidence of transitional care and working with a group of patients and carers, they defined eight transitional care components to be implemented for transitions out of hospital back home. The target population was a range of vulnerable groups, which included people living with cognitive impairment.

The final key components they identified were:

- patient engagement,
- caregiver engagement,

- complexity and medication management,
- patient education,
- caregiver education,
- patients’ and caregivers' well-being,
- care continuity,
- accountability, (Naylor et al., 2017: 4).

The authors concluded that although the emphasis of each component may vary depending on the needs of patients and carers, all elements should be included.

There is similarity in both the above components of transitional care models, (Burke et al., 2013; Naylor et al., 2017) and both outline specific strategies for each domain. However, it has not been established whether either model (Burke et al., 2013; Naylor et al., 2017) are applicable for people living with dementia who return to their care home following hospital discharge. As I outlined in section 1.4.2. NICE guidance on transitions from hospital to community settings in England (NICE, 2015), sets out a broad set of principles for care, but there is not a comparable component of transitional care model with detailed components for hospital to care home transitions in the UK. Determining effective components of transitional care for this particular transition will address the needs of the significant population of older people returning to their care home after a hospital stay.

Furthermore, transitional care has been studied repeatedly for several decades, often focusing on components with variable outcomes. However, this research frequently excludes people living with cognitive impairment. A review of transitional care evidence by Laugaland et al.,(2012) reported that a review on transitional care had been published on average each year in a ten-year period between 2000 to 2010. Several literature reviews report that models of effective transitional care involve multi-components (Naylor and Keating, 2008; Lamantia et al., 2010; Laugaland et al., 2012; Rennke, 2013; Allen, 2014; Chenoweth et al., 2015). Interventions that support the use of a dedicated professional who coordinates the care appear to be the most effective.

Models of effective transitional care vary. Studies by Coleman et al. (2004; 2006) and Voss et al. (2011) included transition coaches. Coaches were either advanced practice nurses or social workers with specialised training to promote patient and carer involvement in their own post-discharge aftercare. (Rennke et al., 2013). Coleman et. al.'s (2004 and 2006) studies tested their Care Transitions Model using randomised control trials which were assessed as having low risk bias by Allen et al., (2014). Their main findings demonstrated that the interventions by transition coaches was effective in lowering re-hospitalisation rates and lowering costs. Voss et al., (2011) used Coleman's Care Transitions Model in their quasi-experimental prospective cohort study. Although this study is lower quality if the gold standard is applied as it was non-randomised, the authors fully account for the differences among their participant groups. Their findings supported a reduction in readmission rates in the groups receiving the intervention from a transition coach. The 'Transitional Care Model' (Naylor, 2004) also uses advanced practice nurses. In the Transitional Care Model, the advanced practice nurse leads care throughout the acute episode. They provide intensive support from discharge planning, ensuring care is delivered when the patient is home and post-discharge support continues with telephone calls and visits (Naylor et al., 2014). Naylor has conducted randomised clinical trials of this intervention with several different populations (Naylor et al.,1999, 2004). Findings demonstrated reduced readmissions and healthcare costs. These were regarded as high quality well conducted trials (Coalition for evidence -based policy 2010). Schnipper et al. (2006) studied interventions from pharmacists, tackling issues relating to medicine errors at transition. This was also a randomised control trial and although it was a single site study design with a relatively small sample size, its findings concur with others showing that professional input and follow up post discharge are beneficial for optimal transitions out of hospital. These models of transitional care that used dedicated professionals were conducted in the US.

In their systematic review of various transitional care intervention studies, Allen et al., (2014) highlighted that success factors were often measured by reduced readmission rates and efficiency savings with limited interventions evaluating patient experience. Rennke et al. (2013) noted in their systematic review on transitional care and patient safety that success in improving discharge practice was variable. They reported that contextual factors were rarely examined making it difficult to judge which models of care and interventions were most beneficial. Piraino et al. (2012), whose systematic review examined if patients included in studies of transitional care interventions were at high risk for rehospitalisation observed that people living with dementia or those experiencing cognitive impairment were often excluded from transitional care studies.

Two studies from the US which included people living with dementia found that people with cognitive impairment can benefit from interventions initially developed for a generic population of older people. One such intervention included face-to-face follow up interventions by an advanced practice nurse (the transitional care model) (Naylor et al., 2014) and another was a telephone follow up intervention by a nurse case manager (Kind et al., 2016). The latter was not deemed to be a research study but a service improvement pilot. Nevertheless, the study involved collection of data over a 24-month period and application of robust outcome measures. Results found that there were fewer re-hospitalisations and an increase in caregiver satisfaction.

In the UK, a qualitative study by Mockford et al. (2017) included people living with memory loss and explored their experiences of hospital discharge. Semi structured interviews and focus groups were conducted with people living with cognitive impairment, their carers and health care professionals, interviews were conducted six and twelve weeks post discharge. Their study revealed a fragmentation of services, a lack of service user involvement and confusion about follow up at hospital discharge. Two focus groups were held with study participants to develop recommendations for smoother transitions out of hospital. Recommendations were developed using the nominal group technique. Although the sample was relatively small and only from two NHS Trusts it does capture the views of people living with cognitive impairment which is often absent from studies. However, although each of these studies focused on the person living with dementia, they were all focused on transitional care when the person returns to their own home and not to a care home setting.

A recent literature review which included seven studies focusing on home based transitional care or avoiding transitions to hospital, identified a dearth of research into the development of evidence-based interventions for transitions for people living with dementia (Hirschman and Hodgson 2018). Common approaches included involving patients and carers in establishing the goals of care, patient and carer education, timely communication of information and creation of inter-professional teams with competencies in dementia care. None of the studies were conducted in the UK. Overall, there is little research especially in the UK about improving transitional care for people living with dementia moving between hospital and care home settings, highlighting the need for this.

In summary, there has been significant academic interest in improving transitional care with some high quality evidence to support effective transitional care interventions. Many of the models of care employ nurses as a dedicated professional to deliver these interventions. However, most of this research has been conducted with older people being discharged to their own homes, and relatively few studies have included people living with dementia. It is therefore difficult to know if these models of care apply to people living with dementia or whether they would be effective for hospital to care home settings. Most of the studies which involved people living with dementia were conducted in the US. There is minimal UK research on transitional care focussing on the needs of people living with dementia. While some of the studies conducted with older people may have included people living with dementia the authors did not distinguish between those with and without cognitive impairment. There is now a compelling need for research to focus on the specific needs of people living with dementia who transition from hospital back to their care home.

1.5.3. The role of nurses in transitional care

It is widely known there are many different disciplines involved in transitional care. In this section I review research evidence to demonstrate that nurses are a key professional in providing and leading transitional care. I give a brief overview of the key challenges nurses experience executing their role and outline the common roles cited in the literature.

1.5.3.1. Nurse led transitional care

Many authors have written about the significance of the nurses’ role in providing transitional care across many health conditions. Zangerle and Kingston (2016) argue that although transitional care is a team effort, nurses play a pivotal role in leading the care. A reason they have a central role is they are often the professionals who have the most consistent contact with the patient and their family throughout their stay in hospital (Nosbusch et al., 2011). In her book on timely discharge, Lees (2012) discusses that although nurse-led discharge models are widespread in NHS Hospital Trusts, there is much variability in how they are implemented. Day et al. (2009) who investigated the role of the discharge coordinator in Ireland, commented the role is often undertaken by a nurse. This was a small qualitative study in a relatively small geographical area, so will have some limitations in terms of transferability. Empirical studies have also demonstrated that nurse-led discharge planning programmes can be effective. Zhu et al. (2015) who conducted a systematic review and a meta-analysis concluded that nurse-led models were more effective than standard discharge care at reducing readmission rates for patients with complex needs. A nurse led discharge service for patients with liver failure was also found to be successful at reducing readmissions and length of hospital stay (Martin et al., 2017).

The Transitional Care Model, referred to in section 1.5.2 is a nurse-led model of care which is well established in the US. It was developed for care of hospitalised older patients with a range of complex needs (Naylor, 1999), and for patients with heart failure, (Naylor, 2004). The model was later developed to include older patients with cognitive impairment (Naylor et al., 2014). It has demonstrated health and economic benefits via several clinical trials and clinical effectiveness studies (Naylor et al., 2018).

The Transitional Care Model has defined key roles for nurses undertaking the intervention. These include care coordination, team collaboration, engaging and maintaining relationships with patients and carers, promoting continuity, managing symptoms and risks, and educating patient and carers to promote self-management. It advocates the use of advanced practice nurses. An advanced practice nurse in the US and UK are recognised as registered nurses who have been educated to master's level and assessed as being competent to perform an advanced level of nursing practice (Parker and Hill 2017; RCN, 2018). In the Transitional Care Model, the advanced nurse practitioner role is described as a key success factor, indicating that leading transitional care requires leadership and advanced nursing skills. There have been adaptations in implementing the model which have included using registered nurses who hold a bachelor's degree (Naylor et al., 2018). Further research is required to explore the effectiveness of such adaptations.

Other nurse researchers have also been interested in identifying effective strategies to deliver transitional care. A team of Canadian researchers formed a panel of multi-professional experts and a family carer representative as part of a consensus study. The aim was to establish a set of nurse-led care interventions for the transitional care of older people with complex needs (Jeffs et al., 2017). The study identified five key effective strategies: educating patients and families, ensuring follow up of medical appointments, using standardised documents for communication, optimising the nurses' scope of practice across transitions and strong leadership and accountability structures. The researchers also noted the need for further research to understand in which contexts nurse led interventions work best (Jeffs et al., 2017). Although the panel was drawn from a range of professions, was multi-disciplinary and knowledgeable about care transitions it did lack a range of perspectives from patients and families. This will have some impact on results as service users have different perspectives from those of professionals. However, the latter two studies share similarities in identifying nursing strategies for delivering transitional care.

In summary nurses are key professionals in leading transitional care. Several nurse-led models are regarded as effective in improving hospital discharge but there is variability in how these models are implemented. A need for further research that investigates the context and adaptation of nurse-led models of transitional has also been identified.

1.5.3.2. Key challenges executing the nurses’ role

Transitional care is complex. In this section I will outline some of the known common challenges, focusing on nurse to nurse communication and nurses communicating across care settings at transition. I highlight this common challenge in providing transitional care is identified by nurses from various countries. I conclude by discussing the role of nurses in providing transitional care for people living with dementia.

The challenges of executing hospital discharge by ward-based nurses were well documented in an integrated literature review of 38 studies predominantly conducted in the US and Australia (Nosbusch et al., 2011). Study dates of the empirical studies in the review ranged from 1991- 2009 and are therefore now rather dated. However, their findings of the common challenges have been replicated more recently (King et al., 2013; Kirsebom et al., 2013; Rustad et al., 2017), demonstrating these issues are long-standing and difficult to overcome. Studies cited in Nosbusch et al. (2011) reported that inter and intra disciplinary communication, time pressures, and role confusion, commonly affected the nurses’ role. Positive experiences occurred when there was a formal process to discharge planning, a clinical pathway, or when standardised instruments were available.

Likewise, more recently the QNI study conducted in the UK found similar challenges with regard to nurse communication (Pellett, 2016). Additionally, two Scandinavian studies reported similar issues. A study by Kirsebom et al., 2013) had a small sample of twenty nurses attending three focus groups, and focussed on hospital to care home transitions. A limitation acknowldeged by the authors was they did not consider data saturation had been reached. Rustad et al.,(2017) explored hospital discharge of older people with hospital-based and community-based nurses. This study was slightly larger and held five focus groups on two separate occasions with a total of thirty nurses. The second group enabled clarification of information gathered from the first group, adding some confirmability of the results. Inadequate nurse to nurse communication and insufficient time to prepare adequately for the transition were identified in both studies (Kirsebom et al., 2013; Rustad et al., 2017). These findings resonated with a study of nurses who worked in skilled nursing facilities in the US (King et al., 2013). The aim of this study was to examine the care provided by nurses when a person was admitted to a skilled nursing facility from hospital. It involved twenty-seven nurse participants from five facilities who participated in interviews or a focus group. Data saturation was an important indicator for sample size in that they continued until they found repetition. However, they did not collect participant demographic data and the differences in work processes, for example, how they communicate with hospital staff could possibly be related to nurses' length of experience or education and training.

The findings by Nosbusch et al. (2011) and in the more recent studies conducted in the UK, US and Scandinavia demonstrate there are historical difficulties in the nurses' role in providing transitional care which remain unresolved. There is also emerging evidence about the way nurses work across care settings which identifies a lack of nurse to nurse collaboration (King et al, 2013; Kirsebom et al., 2013; Rustad et al., 2017). Of particular interest is the study conducted in Sweden (Kirsebom et al., 2013) which investigated both hospital and care home nurses' perspectives of their role and the US study (King et al, 2013) which looked at nurses' roles in skilled nursing facilities. These investigations give some insight into the issues with the interface between hospital and care home settings.

One of the challenges in researching this is the fact that the nurses' role in providing transitional care is multi-faceted (Lees, 2012). Commonly identified roles are now presented to demonstrate the complexity. These include: nursing assessment and decision making about discharge readiness; coordinating care and ensuring continuity; and providing patient education.

1.5.3.3. Nursing assessment and decision making about discharge readiness

Studies from several countries report that conducting a comprehensive nursing assessment is a key function in the discharge planning process. The outcome of such assessments contributes to decision making about safety and discharge readiness. A UK study of hospital nurse perceptions of discharge planning in acute health care noted that gathering a social history is an important element of nursing assessment (Atwal, 2002). This was more consistently carried out on elderly care wards but in cases when history taking was difficult due to mental capacity this was often incomplete. This highlights additional challenges when nursing people living with dementia who may have compromised mental capacity. Other studies have shown that nurses conducting an assessment as early as possible or at admission is a key element for good discharge planning (Watts, 2005; Rhudy et al., 2010; Mabire et al., 2015). One of these studies conducted in Switzerland (Mabire et al., 2015) investigated nursing discharge planning of older patients and its correlation with patient readiness for discharge. This study's strengths include the application of a variety of data collection methods; examining patient records, administering readiness for discharge and hospital anxiety scales and telephone follow up with each participant post discharge. Document review of patient records does however have some limitations as records may not accurately reflect the reality of the experience or in this case the discharge intervention. It also relied on patient recall post discharge about healthcare utilisation after hospital, which also may not always be accurate. Findings identified that the ongoing assessment of the patient while in hospital was a common role of the nurse.

This study and those previously mentioned (Watts, 2005; Rhudy et al., 2010) highlight that nurses have key roles in making decisions about discharge plans. For example, their role is to decide when to involve other professionals in the planning and after discharge care (Watts, 2005; Rhudy et al., 2010). Performing a discharge risk assessment to identify mitigating risk factors for discharge was a routine part of the discharge planning process in Graham et al.'s (2013) study which included a survey of 64 acute care hospital nurses.

In Ireland, nurse discharge coordinators who took part in individual qualitative interviews identified different aspects of assessment commonly undertaken in their role (Day et al., 2009). The assessment of patients' needs included: cognitive assessment, activities of daily living, home environment, social support networks, identification of future care needs and assessment for continuing care. In a care home to hospital study, care home nurses discussed various roles in decision making and preparing the care home resident for transfer to hospital (Kirsebom et al., 2013). This study highlights that in addition to hospital-based nurses, care home nurses also have key roles in providing transitional care.

1.5.3.4. Care coordination and ensuring continuity of care

Several studies from the, US (Rhudy, et al., 2009; King, et al., 2013; Naylor, et al., 2018), Australia (Watts, 2005; Graham, et al., 2013) and Europe (Day et al., 2009; Kirsebom et al., 2013; Mabire et al., 2015; Pellet, 2016) recognise that nurses act as coordinators of the discharge process both to patient's own homes and care homes. It is a challenging role which requires many skills including good organisational skills and bringing together multiple stakeholders to ensure care.

Two studies found similar findings relating to coordinating care A qualitative study conducted by Rhudy et al., 2009) in the US explored staff nurses' decision making in discharge planning. The study included a volunteer sample from only one hospital site which the authors state might limit transferability. A UK mixed methods project (Pellet, 2016) investigated both community nursing and hospital-based nurse perceptions of discharge planning. The project findings were based on the views of over 1000 nurses. Six focus groups of community-based nursing staff of diverse grades and experience were held in different geographical areas throughout England. They also undertook an electronic survey of both hospital nurses (N=186) and community-based nurses (n=608). Those who participated in the survey were self selected and may be more likely to have an interest in transitional care and may also be knowledgeable providing rich data. Additionally, significantly fewer hospital nurses took part which may bring a community bias to the findings. Despite those limitations both studies mention that the nurses' role is wide ranging and includes oversight of all the activities connected with the discharge. This included ensuring resources were available post discharge, e.g. tube feeds, medication, and any equipment (Rhudy et al., 2009; Pellet, 2016).

Studies that have involved either interviewing nurses about their role in discharge or observing nurses undertaking discharge planning, report that such coordination relies heavily on communicating with other team members, patients and families (Watts, 2005; Day et al., 2009; Foust, 2007; Naylor et al., 2018). It is therefore clear that engaging with patients and families is an important element of the nurses' role. However, it was difficult to ascertain from these studies the extent to which nurses engaged with patients and families in transitional care. Graham et al.'s (2013) study involved 68 nurses participating in a self-report survey about their role in discharge planning and risk assessment. Although this was a small survey the response rate was good with 64 of the 68 eligible nurses completing it. The findings identified that engaging with families did not take place with a quarter of their sample. Two additional studies also identified that patient and family involvement was either not discussed or missing from nursing documentation (Watts, 2005; Mabire et al., 2015).

In Rhudy et al.'s, (2009) study, nurses are described as *the 'hub', 'the keeper of everything'*, of the discharge process. Graham et al.'s (2013) survey of nurses revealed this coordinating role can be complex and time consuming. It was found that nurses were required to attend discharge planning meetings, make many follow up calls, and complete numerous referrals as well as meet the ongoing care needs of the patient (Rhudy et al., 2009; Day et al., 2009*).*

From the care home nurse perspective, coordinating with the hospital to establish the right follow up care has been shown to be a key component of their role (Kirsebom et al., 2013; King et al., 2013). There was also evidence that care home nurses actively engage with families about decisions to transfer their relative to the hospital. Engaging with families and managing family dissatisfaction about the transition was also discussed by nurses working in skilled nursing facilities when patients were transferred there from hospital (King et al., 2013).

1.5.3.5. Patient education

Patient education is often cited as a key activity in transitional care (Burke et al., 2013; Naylor et al., 2017; Petrozello, 2017). A study investigating discharge planning revealed that patient education was mostly undertaken by physiotherapists, and rarely by nurses (Mabire et al., 2015). An earlier US study set in a surgical unit which investigated discharge planning as part of everyday nursing practice, observed that although patient education was often provided by nurses it was one of the most common elements that was not documented (Foust, 2007). Regardless of its recognition as an important activity within the discharge process there appears to be unclear accountability for its delivery.

1.5.3.6. Role of nurses in providing transitional care for people living with dementia between hospital and care home settings.

People living with dementia face many transitions throughout the trajectory of the condition from initial diagnosis to the end of life. These transitions involve diverse levels and locations of care. Nurses can play an important role in helping people living with dementia and their families to navigate these difficult transitions (Rose and Lopez 2012). As I identified in section 1.5.2 a small body of evidence has identified nurses as having an instrumental role in providing transitional care when a person living with dementia transfers from hospital back to their own home (Naylor et al., 2014 and Kind et al., 2016). There is paucity of evidence, however, of the nurses' role in providing transitional care between hospital and care home settings for residents living with dementia.

In summary, the investigative work conducted on the nursing role in transitional care have used a variety of different study designs. They included a clinical trial, case note analysis, surveys, observations and interviews. However, most of the studies used qualitative approaches. There are some limitations of the evidence in that some of the study samples were small and some were self selecting. Studies were conducted in a range of health care systems from different countries. Despite these limitations common issues were identified. Studies have shown that nurses have multiple roles in providing transitional care and many face challenges in fulfilling their role. The complexity of their role demands nurses to be highly skilled in a range of interventions but particularly in communicating with all involved. One model recognises transitional care as a distinct role, to be undertaken by nurses who can perform an advanced level of nursing practice. However, most transitional care roles are undertaken by registered nurses as part of their everyday job, either way it has been noted the role requires strong leadership. Many of the studies investigating nurses' roles in transitional care focus on the hospital nurse experiences, although a small body of evidence exists about community-based nurses. There is very little available evidence of the role of hospital and care home nurses when care home residents living with dementia transfer between these two settings, and how they interact with each other. None have been identified from the UK making a compelling argument for research to be conducted in this area.

1.6. Chapter conclusion and structure of thesis

What this chapter has found

This chapter has shown that in the UK ensuring good transitional care outcomes for older people who leave hospital has been a significant challenge. This is despite substantial focus from government to address care improvement for people living with dementia through several initiatives: driving forward the integration of health and social care, recognising the central role of nurses in dementia care and recognising that people with dementia may have specific needs during transitions.

I have provided evidence that people living with dementia in care homes live with co-morbidities and as such are at risk of frequent transitions into hospital. This means care home nurses are key players in providing community-based health care and need to collaborate with hospital-based nurses.

I have presented research evidence of components of effective transitional care for older people returning to their homes and interventions which can improve the transitional care experience for this population. I noted that most of this evidence is from the US and the relevance of this for the UK is unclear. Studies have mostly focused on hospital to own home transitions and have frequently excluded people living with dementia. As such, the evidence base for interventions for people living with dementia is not well developed. Likewise, hospital to care home transitions has been mostly conducted with older people and much of this research has not been undertaken in the UK.

I have demonstrated that we know nurses have a central role in providing transitional care. There is emerging evidence about hospital and care home nurses’ roles in providing transitional care but this is not from the UK perspective.

The gaps identified in our knowledge and aims of this thesis

We now need to understand:

- UK hospital and care home nurse perspectives of their role in providing care for people living with dementia who transfer between hospital and care home settings.
- Nurses’ perspectives on what facilitates optimal nursing care when people living with dementia return to their care home after a hospital stay.
- The experiences and outcomes of care for people living with dementia undergoing a transition from hospital to a care home or similar facility.

The next steps in addressing the research aims are to conduct a systematic review of the literature on the experiences and outcomes of care of people living with dementia who transfer between hospitals and care homes from the perspectives of the stakeholders involved (people living with dementia, their families, and health care professionals).

In conclusion, research to date on the transition from hospital back to the care home has not fully addressed the experiences and outcomes for people living with dementia. There is a gap in the UK literature on the perspective of this transition from the key professionals, nurses who are often responsible for leading the care at this transition.

The aim of this thesis is to address the gaps in this research by systematically identifying and summarising the available evidence and exploring nurse perspectives of their role in providing transitional care of care home residents living with dementia who transfer between hospital and care home settings.

1.6.1. Structure of this thesis

In chapter two, I present the method and findings from the systematic literature review. I conclude with confirming the research problem and gap in the literature, stating the aims and research questions which I address in my study.

In chapter three I detail the research paradigm I have adopted, a qualitative descriptive study underpinned by a critical realist perspective. I explain why I chose this approach.

In chapter four, I present the research methods I used to conduct this study; interviews and focus groups and the rationale for doing so. I provide details of the sites I recruited and the sample of hospital and care home nurses.

The findings of the first research question, '*how do hospital and care home nurses describe their role in providing care people living with dementia who are returning to their care home after a hospital stay?*' are discussed in chapter five.

The findings to the second question, '*what are the facilitators for optimising nursing care for people living with dementia returning to their care home from hospital*?' are reported in chapter six.

The findings to the third research question '*does the care provided by hospital and care home nurses, align to best practice guidance* (Naylor et al., *2017)?'* are presented in chapter seven.

In the final chapter, I present a brief summary of the findings, and discuss their implications for policy, practice and research. The strengths and limitations of the study are also identified.

Chapter Two: Stakeholder perspectives of care for people living with dementia moving from hospital to care facilities in the community: a systematic review

2.1. Introduction

In Chapter one I established that most research about transitional care has been conducted with those transitioning out of hospital back to their own homes and that the majority of these studies did not include people living with dementia. Additionally, I identified that nurses have a central role in providing transitional care, but little is known about their role in providing transitional care to people living with dementia. I argued there was a need to understand the experiences and outcomes of care of people living with dementia who transition between hospital and care homes from the perspectives of nurses who provide this care. Here in chapter two I present how I aimed to address this by conducting a systematic literature review but was unable to achieve this fully due to limited available evidence. I describe how I therefore developed my review question to include evidence which related to a broader range of perspectives of the experiences of care of people living with dementia when they transition from hospital to a variety of similar community care settings, not only to care homes.

I describe why I chose to undertake a systematic review as opposed to other methods and then describe the search strategy, the quality appraisal of the papers and how I conducted a narrative thematic analysis of the findings. The review findings are presented in four themes focused on: preparing for transition, quality of communication, inconsistencies in quality of care, family carer engagement and roles of the family carers. I conclude by discussing the implications of the findings for clinical practice and further research.

2.2. Review methods

2.2.1. Developing the review question

In the development phase of the review, I conducted a scoping search which revealed very little international literature about transitions from hospitals to care homes focused on experiences and outcomes for people living with dementia. Some studies identified investigated transitions to a broad range of community care facilities. These facilities included skilled nursing facilities, or short-term care facilities where people may reside to receive rehabilitation care before either going back home or onto a care home. Similarly, initial attempts at restricting the search to literature on nurse perspectives of their role in this transition also identified very few studies. I therefore broadened the scope of this review to include a range of community care facilities as I considered limiting to just care homes would provide insufficient evidence to answer my question. I also widened the scope to include all stakeholder perspectives. I considered a broader understanding of the issues related to this transition would be illuminated including the barriers and facilitators in providing nursing care. Therefore, the final review question was:

What are the experiences and outcomes for people living with dementia who transfer from hospital to a care home or similar community care facility, from the perspectives of people living with dementia, their families and health and social care professionals?

2.2.2. Rationale for a systematic review

There are several ways of undertaking literature reviews. Pare et al. (2015) identified nine different literature review methods, each addressing different aims and types of research questions. Pare and Kitsiou (2016: 172) state there is not a hierarchy of review method, as each one has strengths and weaknesses, but they emphasise the importance of selecting the review type which would best answer the review question. For example, researchers undertaking a traditional narrative review will have a broad topic scope (Pare and Kitsiou, 2016). Such reviews are comprehensive but do not always follow a predefined approach (Pare et al., 2015). As a result the method relies on the authors' experience and expertise, and this subjectivity may bring bias to the review and its conclusions (Cipriani and Geddes, 2003). In contrast systematic reviews are chosen to answer narrowly focused questions and where there is a requirement to use replicable methods so that the results can be reproduced (Pare and Kitsiou, 2016). According to Munn et al. (2018a: 2) a systematic review should be conducted for the following wide-ranging reasons: when international evidence is required on the topic, when there is a need to study interventions or practice to confirm or refute effectiveness, to establish any gaps in the evidence and produce summaries to guide practice. A feature of systematic reviews is that study quality is assessed, and this informs the synthesis and summary (Munn et al., 2018a: 3). Munn et al. (2018b) also identified a typology of systematic reviews including reviews that study effectiveness, experiences, economic evaluation, incidence, diagnostic accuracy, and several others. Systematic reviews are more frequently accepted for publication in academic journals (Pae, 2015), but it has been argued that the popularity of published systematic reviews, often addressing similar research questions have resulted in discordant findings (Pare et al., 2015).

Review questions that are exploratory in nature lend themselves to a scoping review (Pare and Kitsiou, 2016). Scoping reviews are relatively new - the first framework for conducting a scoping review was developed fifteen years ago (Arskey and O'Malley, 2005). Since then, there have been further developments in the methodology and five years ago a working group produced formal guidance for conducting a scoping review (Munn et al. 2018a). Munn et al. (2018a: 2) suggest scoping reviews are suitable when researchers want to find out the available evidence in a given field, when there is a need to: identify key characteristics of a concept, clarify concepts and/or definitions, explore the types of research conducted in the field and determine gaps in research. They can also be a precursor to a systematic review. Scoping reviews also use robust methods in searching and data extraction and to map the evidence. However, as the aim of the scoping review is to present the evidence there is not a requirement to critically appraise it or produce a summary of the findings to inform guidance (Munn et al., 2018a).

I chose to undertake a systematic review because their aim is to include important information about the quality of available evidence for the development of evidence-based practice (Ridley, 2012), in my case, how to improve the transitional care experience and outcomes of people living with dementia who move from hospital to care homes. Using a rigorous systematic approach to provide a synthesis of an issue such as perspectives of this transition would give focus to the overall PhD study. Although this review was intended to include all study designs, it was envisaged most studies would be qualitative. Qualitative systematic reviews can develop a broad understanding of issues and are useful for recognising barriers and facilitators of how services are delivered (Munn et al., 2018b). Making it particularly valuable to my interest in how the nurses' role can improve experiences of care.

I followed the guidance set out in the Centre for Reviews and Dissemination guidance for systematic reviews (CRD, 2009). The protocol was registered with Prospero (International database of prospectively registered systematic reviews in health and social care). PROSPERO 2017. CRD42017082041 (Lord and Richardson, 2017). The systematic review was published in BMC Geriatrics (Richardson et al., 2019) and is available in Appendix 1. The literature search for this review was updated in January 2020 and additional included papers incorporated into the findings, which are presented here.

2.2.3. Search Strategy

I developed a search strategy in the database CINAHL (table one). No date restriction was imposed. I did not want to narrow opportunities for finding studies that involved people living with dementia and there was no policy rationale that would suggest that restricting the dates would provide a more relevant review. I adjusted the search strategy to run on five other electronic databases including ProQuest, EMBASE, Medline, Psych INFO, and Scopus. The terms 'Dementia' or 'Alzheimer's disease' or 'cognitive impairment' were used in combination with 'transitional care', or 'discharge planning', or 'transfer, discharge', and with 'hospitals' or 'care home', or 'residential care' or 'nursing home' or 'skilled nursing facility'. Additional papers were identified by hand searching the reference lists of the included papers, relevant systematic reviews and papers suggested by other experts. The first search was conducted in April 2018 and the second to update it in January 2020.

Table one: (CINAHL search strategy) January 2020

	Search terms /combination	Results
1	(MH "Dementia+")	65,655,
2	(MH "Alzheimer's Disease")	(28,893)
3	“cognitive impairment”	(30,708)
4	1 OR 2 OR 3	(88,378
5	(MH "Transfer, Discharge")	(5,411)
6	(MH "Transitional Care")	(1,419)
7	(MH "Discharge Planning+")	(4,739)
8	5 OR 6 OR 7	(11,260)
9	(MH "Hospitals+")	(108,115)
10	(MH "Residential Care +")	(7,129)
11	"care home"	(2,546)
12	(MH "Skilled Nursing Facilities")	(3,778)
13	(MH "Nursing Homes+")	(25,984)
14	9 OR 10 OR 11 OR 12 OR 13	(140,587)
15	4 AND 8 AND 14	(89)

2.2.4. Inclusion and Exclusion Criteria

This review focuses on both ‘experiences’ and ‘outcomes’ of transitional care for people living with dementia. It was at times difficult to determine differences between ‘experiences’ and ‘outcomes’. For this review, the term ‘experience’ was defined as capturing the emotional and psychological responses to being involved in the transitional care process, for example feeling ‘unprepared’ or ‘frustrated’. ‘Outcomes’ related more to effects, consequences and impact during or following the transition, for example ‘fully engaged in discharge planning’ or ‘communication failures’, or ‘abrupt changes in analgesic medication’. The definition of transitional care developed by (Coleman et al., 2003) and (Naylor et al., 2011) was used as highlighted in section 1.5.1.

Studies were included if they reported:

- The experiences and/or outcomes of care for people living with dementia or cognitive impairment (‘dementia’ and ‘cognitive impairment’ as defined by the authors of the individual studies), moving from hospital to short or long term care settings (e.g., sub-acute, rehabilitation, skilled nursing facilities, care homes, including those returning to their care home after a hospital admission).

- Experiences and outcomes of the people living with dementia and/or their families were reported separately from those without cognitive impairment.
- Activities such as discharge planning from hospital to a care facility and any intervention or service people received during and following transition or the period waiting for long-term care placement.

Papers were excluded if:

- The majority of patients/residents referred to in the study were older people without cognitive impairment (we were led by the authors of the individual studies in their descriptions of ‘older’ and ‘cognitive impairment’).
- The majority of patients/residents were being discharged back to their own home (own home refers to a domestic setting, those returning back to their care home for example were not excluded)
- The study did not report on experiences or outcomes of care
- The study was not written in English
- The study did not report primary research published in peer review journals.

2.2.5. Data Extraction

I exported all retrieved references into Endnote reference management software version X7 and duplicates were removed. I read and screened the titles and abstracts of the retrieved studies. One of my supervisors (KL) and I independently read all retained papers from both searches. The decision to include or exclude papers was agreed by consensus. A third reviewer was available if consensus could not be reached but recourse to a third reviewer was not required. Data were extracted from the included papers using a pre-determined set of criteria, which I developed in consultation with supervisors after testing with a small number of papers. The final information extracted was, location, study setting and service descriptions, study methods, study aim, study participants, main findings (See tables three and four).

2.2.5.1 Choice of quality assessment tool

KL and I independently assessed each paper for quality, using checklists developed and used by other authors (Mukadam et al., 2011, Boyle, 1998). A range of quality appraisal tools were considered, and the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) was originally chosen, because it used a summary scoring system and was easy to use. When testing the MMAT on the qualitative papers retrieved for this review, it was noticed papers often scored highly, even though it was considered by KL and myself that the particular paper under review had some flaws. Crowe and Sheppard (2011) report summary scores can sometimes be misleading as they hide deficits in articles and may not identify strengths in other areas. A further rationale for using the selected tool by Mukadam et al., (2011) and Boyle, (1998) was it had been successfully used before by KL and colleagues (Lord et al 2015). It was preferred because of the flexibility to weight specific criteria, deemed to be important markers of quality as deduced from the research literature.

This instrument awards a point if the paper meets each criterion on the checklist, a maximum of six for both quantitative and qualitative and five for intervention studies, with higher scores signifying higher quality (Table two). Criteria were weighted to define higher quality studies as previously described by (Lord et al., 2015). Quantitative studies were characterised as higher quality if they: clearly defined the target population, used standardised data collection, measures used were valid and reliable (criteria 1,4,5,6). Qualitative papers were characterised as higher quality if they used a clearly defined recruitment method, had clearly stated inclusion and exclusion criteria, standardised data collection and involved two or more independent raters in data analysis (criteria 2,3,5). Intervention studies were characterised as higher quality if they appropriately allocated participants to intervention and control groups, ensured all participants who entered the trial were accounted for, collected data and followed up all participants in the same way (criteria1,3,4). Quality assessment was agreed by consensus, a third reviewer was available if consensus could not be reached but was not required.

Table two: Quality Assessment Tool. *(Lord et al. 2015: 1303)*

Quality assessment tool for Quantitative studies	Quality assessment tool for Qualitative studies	Quality assessment tool for Intervention studies
(1) Was the target population defined by clear inclusion and exclusion criteria?	(1) Were the aims of the research clearly stated?	(1) Were participants appropriately allocated to intervention and control groups? (was randomisation independent?)
(2) Was probability sampling used to identify potential respondents (or the whole population approached)?	(2) Was a clearly defined method of recruitment used and explicit inclusion/ exclusion criteria described?	(2) Were patients and clinicians as far as possible 'masked' for treatment allocation?
(3) Did characteristics of respondents match the target population, i.e. was the response rate ≥80% or appropriate analysis included comparing responders and non responders?	3) Was the process of data collection explained clearly? Was data collection standardised?	(3) Were all patients who entered the trial accounted for and an intention to treat analysis used?
(4) Were data collection methods standardised?	4) Did the researchers attain saturation of data?	(4) Were all participants followed up and data collected in the same way?
(5) Was the measure used valid?	(5) Was the process of data analysis sufficiently rigorous, i.e. ≥2 raters, some method of resolving discrepancies?	(5) Was a power calculation carried out, based on one or more outcomes of interest?
(6) Was the measure used reliable?	6) Have the findings been validated by participants?	

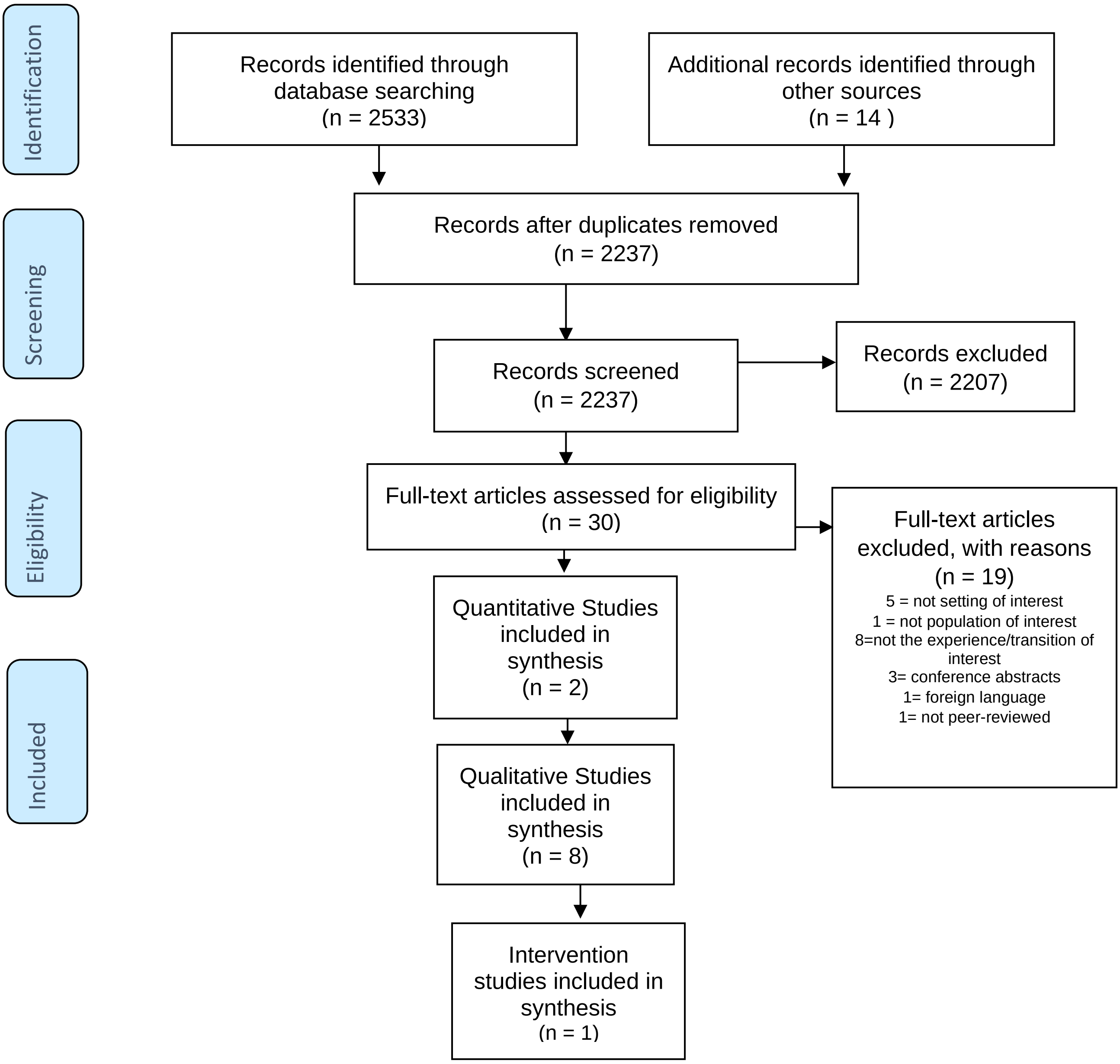
2.2.6. Narrative thematic analysis

I read the papers multiple times and extracted the findings. I used a constant comparative method of continually moving between the findings of each study (Booth et al., 2016). I coded the findings and grouped them into related categories/themes. A second reviewer (KL) checked these for accuracy. Four recurring themes pertaining to experiences and outcomes were identified from the included papers, these are described in detail in section 2.4.

2.3. Results

After removal of duplicate papers, the number of retrieved titles and abstracts screened was 2237. There were 30 papers that potentially met the inclusion criteria, and these were subject to full text scrutiny. In the most recent search two further studies were identified since April 2018. In total 11 papers met the inclusion criteria (PRISMA Figure one) in January 2020. Most studies meeting the inclusion criteria used qualitative methodology, possibly due to the nature of the review question, focusing on perspectives. Eight papers reported qualitative studies, two were quantitative and one was a pre/post intervention evaluation. One study (Rhynas et al., 2018) was close to meeting the inclusion criteria but was excluded because its narrower focus on decision making rather than the experiences and outcomes of care at transition. The 11 studies are summarised in Table three (Study settings and service descriptions) and Table four (Study methods and quality appraisal)

Figure one: Prisma Diagram



Included studies were published between 2011 and 2019. Six papers were from Australia (Bauer et al., 2011; Bloomer et al., 2016; Digby et al., 2012; Fitzgerald et al., 2011; Kable et al., 2015; Renehan et al., 2013) with two reporting findings from the same study (Bauer et al., 2011 and Fitzgerald et al., 2011). Three were from the United States (US) (Gilmore-Bykovskyi, 2017; Gilmore-Bykovskyi et al., 2019; Prusaczyk et al., 2019), one from the UK (Emmett et al., 2014) and one from Canada (Kuluski et al., 2017).

Two studies elicited perspectives of people living with dementia (Digby et al., 2012; Emmett et al., 2014). The authors interviewed people living with dementia, N=8 and N=29. Additionally, Emmett at al. (2014) conducted ethnographic observations over 111 days. Renehan et al. (2013) analysed the care records of people living with dementia to determine whether the transition programme was helpful to those residents with behavioural and psychological symptoms. Two studies also analysed care records of people living with dementia. Gilmore-Bykovskyi et al. (2019) analysed 343 medical records to ascertain analgesic prescribing to individuals with dementia being discharged from hospital to a skilled nursing facility. Prusaczyk, et al. (2019) reviewed 126 patient records and compared them to records of eighty-nine patients without dementia to examine differences in the transitional care provided.

Using interviews and or focus groups, five studies (six papers) included the perspectives of family members (Bauer et al., 2011; Fitzgerald et al., 2011; Bloomer et al., 2016; Emmett et al., 2014; Kuluski et al., 2017; Renehan et al., 2013) and only four studies sought the views of health and social care professionals (Renehan et al. 2013; Kable et al., 2015; Gilmore-Bykovskyi et al., 2017; Emmett et al., 2014).

The combined number of participants from each category was 517 people living with dementia which includes the number of medical records reviewed N=480, 95 family members and 125 healthcare professionals. A range of health and social care professionals were represented and included: medical staff working in hospitals and the community (Kable et al., 2015; Emmett et al. 2014), allied health care professionals (Kable et al., 2015; Renehan et al., 2013; Emmett et al., 2014), social workers, health care assistants and a professional advocate (Emmett et al., 2014). The largest group of health and social care professionals were nurses including those working in hospitals (Renehan et al. 2013; Emmett et al. 2014; Kable et al. 2015), community care facilities (Renehan et al., 2013; Gilmore-Bykovskyi, 2017) and in GP practices (Kable et al., 2015).

Staff working in care homes were included in two studies (Kable et al., 2015; Renehan et al., 2013). One of these also included a range of staff who worked within the transition care programme: personal assistants, diversional therapists, team leaders and managers were also cited as participants (Renehan et al., 2013).

Although the focus of the studies was not about the specific pathway into the community care facility, (for example if this was the first time of moving into a facility, returning to a care home, or transitioning for a short term basis) some of these pathways from hospital were evident. The most common pathway was transitioning to a facility for short term care before going home or until a long-term care placement was found. There were seven studies (eight papers) including participants who had experienced this transition (Bauer et al., 2011; Fitzgerald, et al, 2011; Bloomer et al., 2016; Digby et al., 2012; Gilmore-Bykovskyi, et al., 2017; Gilmore-Bykovskyi et al., 2019; Kuluski et al., 2017, and Renehan et al., 2013). The pathway least studied was of a person returning to their care facility/care home from hospital with two studies reporting on this experience (Kable et al., 2015 and Prusaczyk et al., 2019). Table five outlines which pathways were identified in each study.

Study settings where transitional care took place were varied but the majority were short-term stay settings, for example facilities providing rehabilitation and sub-acute care. The description and definitions of settings or services and the transition points can be found in table three. Most studies focused on the provision of transitional care, including discharge planning, how decisions are made, and the processes involved in the transfer.

2.3.1. Methodological quality

The study quality appraisal is tabulated in table four. Both quantitative studies were rated as high quality as they both achieved maximum scores. Seven of the qualitative studies were rated as high quality, with scores ranging from four to six and all meeting the weighted criteria. The one lower quality study score (Digby et al., 2012) reflects insufficient information being given on the process of analysis and whether at least two raters had been involved. Word restrictions of journal papers can sometimes influence authors to leave out information, this lower score reflects the fact that the authors did not describe their process, not necessarily that they did not do it. The pre/post intervention evaluation (Renehan et al., 2013) was rated as low quality, as it met only one out of the five criteria, the low score relates to not having a comparison group and experiencing administrative issues resulting in incomplete records and measures only available for eight out of the 11 records.

Table three Description of settings/ services

Authors and country	Study setting(s) / care service	Description or definitions of settings and or services	Transition points where perspectives are elicited
Bauer et al., (2011) Fitzgerald et al. (2011) Australia.	Rehab facility (n=8). Residential care (n=8).	Rehabilitation facility, short-term restorative care before discharge back home or to residential care. Residential care – Long term care facilities providing high and low-level care.	Family carers of people living with dementia interviewed two months after discharge about their experiences of the transitions.
Bloomer et al., (2016) Australia.	Geriatric evaluation and management facility.	Provides rehabilitation to optimise function and determine future care needs. Majority of patients are transferred from acute care, a third of patients move to residential care.	Family carers of people living with dementia were interviewed after admission into the Geriatric evaluation and management facility. Experiences were elicited about transitioning through the system from acute hospital.
Digby et al., (2012) Australia.	Geriatric rehabilitation facility (sub-acute facility).	A facility providing in-patient evaluation, and management of older patients with complex needs, most transferred from acute care setting.	People living with dementia interviewed between 1-5 days after transferring from hospital to the facility.
Emmett et al.,(2014) UK.	Three general elderly care wards in two hospitals.	Acute hospital care providing medical care for short-medium term acute episodes of care.	Person living with dementia and family carer interviews were conducted at point of discharge and three months post discharge. Health and social care perspectives elicited about discharge planning and decision-making.
Gilmore-Bykovskyi et al., (2017) USA.	11 Skilled nursing facilities (SNF).	SNF’s provide high level of medical and nursing care. Services are provided for a limited time but can be more longer-term.	Nurses were interviewed about care when people with dementia had transitioned from hospital into the skilled nursing facility.
Gilmore-Bykovskyi et al., (2019)	Two Hospitals and a skilled nursing facility.	One urban academic hospital and an urban community hospital providing	Individuals with dementia care records were retrospectively examined over a five-year period for analgesic prescribing

USA.		acute care and a skilled nursing facility providing sub-acute care.	patterns and focussed on the last 48 hours of hospital admission and the discharge to the skilled nursing facility.
Kable et al., (2015) Australia.	Acute tertiary facility GP Practice Residential aged care setting.	Acute hospital care Community care Long-term care facility.	Both hospital-based and community-based health care professional about the transitional care of people living with dementia at the transition points of leaving hospital into the community.
Kuluski et al., (2017) Canada.	Hospital setting, (alternate level of care (ALC)).	Patients who are fit for discharge but are waiting for long term care placement or community support.	Family carers perspectives were elicited whilst the patient (with cognitive impairment) was receiving the alternative level of care.
Prusaczyk et al., 2019 USA.	Acute hospital setting.	An urban tertiary teaching hospital.	Care records of patients over 70 who experienced at least an overnight stay in hospital. Sample was stratified by diagnosis of dementia and records retrospectively examined for type of transitional care interventions received.
Renehan et al., (2013) Australia.	Transitional Care programme which was called ‘Transition Care Cognitive Assessment and Management Pilot’ (TC-CAMP).	Dedicated (short term) beds within a residential aged care facility, used specifically for people living with dementia who were medically fit to be discharged from hospital and would be transferring to long term care.	Health and social care professionals from all of the transition points, hospital, TC-CAMP and discharge destination care home. Family carers perspectives were gathered post discharge from the TC-CAMP.

Table four study methods and quality appraisal

Study	Methods	Participants	Aims	Main findings	Quality appraisal					
					1	2	3	4	5	6
Bauer et al., (2011). Fitzgerald et al., (2011).	Semi-structured interviews.	25 carers.	Understand family carers experience of discharge planning, support, and what improvements could be made.	Breakdown in communication: lack of coordination. Hospital staff having poor capability for caring for people with dementia. Inadequate preparation, undervaluing family carer as a resource.	✓	✓	✓	✓	✓	✓
Bloomer et al., (2016).	Semi-structured interviews / conversation approach.	20 carers.	Explore the experience of carers through hospitalisation and rehab with a view to transitioning to residential care.	Families found the process difficult decisions about moving into care was challenging, carers would like to be better informed, concerns about the care provided whilst in hospital.	✓	✓	✓	x	✓	x
Digby et al., (2012).	Semi – structured interviews.	8 people living with mild to moderate dementia, transferred in the preceding 5 days.	Understand the experience of people living with dementia (plwd) who are settling in after transfer from acute hospital to sub-acute facility.	People felt disorientated. Participants felt patronised by staff and unsettled by the loss of control in the environment. Family support was a great consolation.	✓	✓	✓	x	x	x
Emmett et al., (2014).	Ethnographic approach using observation, interviews and focus groups.	35 health and social care prof 29 patient interviews and cases 28 nominated relative.	Explore the role of relatives during the discharge planning process and when decisions are made to discharge plwd from hospital either back home or to long-term care.	Roles relatives play: advocates, information gatherers, and care takers which included assisting in care. Lack of information and inadequate preparation. Conflicts of interest between relatives and patients.	✓	✓	✓	✓	✓	✓

Gilmore-Bykovskyi et al., (2017).	Focus groups and semi structured interviews.	40 licensed nurses from SNF's.	Examine SNF nurses' perspectives regarding experiences and needs of plwd during hospital-to-SNF transitions.	Inadequate preparation of person, being excluded from care decisions. Unprepared receiving environment. Role of timing of transition. Inadequate information about social and health needs and behaviour related symptoms. Staff feeling ill-equipped to provide safe care. Misalignment between hospital pressures and transitional care needs of patient.	✓	✓	✓	✓	✓	✓
Gilmore-Bykovskyi et al., (2019).	Retrospective cohort study of electronic medical records and Medicare data.	343 Medical records of Medicare beneficiaries with dementia.	Examine analgesic medication use and prescribing patterns in the last 48 hours of hospitalization and upon discharge to SNF among stroke and hip fracture patients with dementia.	318 patients received analgesic medication within the last 48 hours of hospitalization. 72 experienced abrupt discontinuation of that analgesic on discharge. 297 patients had an analgesic medication prescribed in their discharge summary, of these, 112 experienced abrupt addition of analgesic medication that had not been administered in the last 48 hours of hospitalization. 73 patients experienced potentially abrupt changes in type of analgesic medication at transition.	✓	✓	✓	✓	✓	✓
Kable et al., (2015).	Focus groups.	33 Health care professionals (HCPs) of which 21 hospital staff	Explore HCP perspectives on the discharge process and transitional care arrangements for plwd and their families.	Acute staff experienced difficulty caring for people with dementia. Patients were over sedated on return. System pressures to discharge. Inadequate preparation time for work capacity issues. Inadequate communication	✓	✓	✓	x	✓	x

		12 community staff		between health professionals working in different settings.						
Kuluski et al., (2017).	Semi structured interviews.	15 family members across 12 interviews.	Understand the hospital experience of carers of patients who require an Alternate Level of Care,	Inconsistent quality of care, non-medical needs and characteristics ignored. Families addressing the gaps in the system. Confusing process.	✓	✓	✓	✓	✓	x
Prusaczyk et al., (2019).	Retrospective medical chart review.	Records of 126 patients with dementia (42 surgical,84 non-surgical and 84 patients without dementia 28 surgical and 56 non-surgical.	Understand the transitional care delivered to older adults with dementia compared to those without dementia.	Patients with dementia were more likely to be discharged to a facility. Providers were significantly less likely to obtain accurate medication histories from patients with dementia. Patients with dementia and family caregivers were significantly less likely to receive education related to their in-hospital medications, diagnoses, follow-up needs, whom to contact after discharge, medication regimens after discharge and symptoms after discharge. Among patients who received education about their medications, patients with dementia were significantly less likely to understand the education (per provider assessment)	✓	✓	✓	✓	✓	✓

Renehan et al., (2013).	Interviews, focus groups, file audits.	11 cases of which 8 had completed records, 7 family members took part in the qualitative evaluation, 17 staff from the hospital, facility and destination facility.	Evaluate the transitional care cognitive assessment management pilot. Identify barriers and enablers to implementation.	Significant reduction in agitated behaviours once moved to the transitional facility. Adequate communication provision and valued the clinical nurse consultant. Discharge destination facilities reported information timely and thorough.	Intervention study				
					x	x	x	✓	x

Table five Pathways from hospitals to care facilities

Studies	Pathway A Person returning to care facility from hospital	Pathway B Person discharged to long term care facility for first time	Pathway C Person transferred to short-term care before long term care placement /home
Bauer et al., (2011) Fitzgerald et al., (2011) (Australia).		✓	✓
Bloomer et al., (2016) (Australia).			✓
Digby et al., (2012) (Australia).			✓
Emmett et al., (2014) (UK).		✓	
Gilmore-Bykovskyi et al., (2017) (USA).		✓	✓
Gilmore-Bykovskyi et al., 2019 (USA).		✓	✓
Kable et al., (2015) (Australia).	✓	✓	
Kuluski et al., (2017) (Canada).			✓
Prusaczyk, et al., (2019) (USA).	✓	✓	
Renehan et al., (2013) (Australia).			✓

Table Six: Summary of experiences and outcomes from different perspectives

Stakeholders perspectives	Theme: Preparing for transition		Theme: Quality of communication		Theme: Inconsistencies in quality of care		Theme: Family engagement and roles of family	
	Experiences	Outcomes	Experiences	Outcomes	Experiences	Outcomes	Experiences	Outcomes
People living with dementia.	Unable to remember preparation.	Disorientated by move.	Feeling unsettled and powerless. Feeling emotions.	Excluded from care decisions and decision making. Less likely to receive education about various aspects of their in-hospital and follow up care. Less likely to understand any education provided.	Feeling patronised and unsettled.	Lack of personal empowerment. Lack of understanding from staff. Abrupt changes in analgesic medication with some experiencing gaps in pain control. Received some transitional care interventions but fewer overall than those without dementia.		Family support provides comfort
Family carers.	Insufficient preparation.	Undermined ability to give informed opinion re planning. Lack of communication. Not receiving education on follow up care.	Feeling communication could be better. Appreciation of access to named professional.	Breakdown of communication between family and hospital. Care decisions made on insufficient information. HCPs fail to communicate adequately with		Assumptions made by HCPs about psychosocial needs of the people living with dementia. Concerns about standards of care.	Feeling unappreciated and frustrated when excluded. Tension and family conflict about care decisions. Stressful experience	Families filling gaps in care system helping with hands on care and advocacy. Family support provides comfort to the

				person with dementia. Some reported adequate communication. Attending regular meetings. Difficulties getting hold of clinicians.		Some reported reduction in agitation, improved socialisation and health outcomes.	leading up to discharge.	person with dementia.
Health and Social care professionals (HCPs).	Person with dementia feeling stressed. HCPs feeling pressured. Unsettling for person with dementia.	Not preparing the person properly, unable to understand event. Quick transfers, insufficient time to prepare documentation. No time to organise environment and order equipment. Transfers late in day.	Stressful experience for person with dementia and family. Poor start to care home experience for person with dementia and family.	HCP's often unable to obtain accurate medication history from patient. Care decisions made on insufficient information. HCPs fail to communicate adequately with person with dementia. People with dementia excluded from care decisions. Difficulties with individual care planning and providing care continuity. Judgment of care facility as being inefficient. Some reported timely and	Feeling ill-prepared and ill-equipped about how to care for people living with dementia.	People living with dementia returning to facility over sedated. Not having original health care needs met. Under reporting of behavioural symptoms. Insufficient workforce to provide care.	Conflicts of interests between family members and person living with dementia.	Smoother transition when working with families. Working with family members could be difficult.

				comprehensive information. Failure to provide GP with discharge summary.				

2.4. Findings

Four recurring themes pertaining to experiences and outcomes of care were identified including: preparing for transition, quality of communication, inconsistencies in quality of care, carer engagement and roles of the family. Some of these overlapped. For example, preparation for transitions was closely linked to the quality of communication given when preparing for transfer. Quality of communication was also linked to carer engagement. A summary of the experiences and outcomes of care from the different stakeholder perspectives can be found in table six. The table identifies the similarity in experiences and outcomes across the four themes provided by different stakeholders. Although stakeholders were diverse there were striking similarities in perspectives. These four themes will now be described in detail.

2.4.1. Preparing for transition

This theme is about the degree of preparedness that was felt by all stakeholders: people living with dementia, their carers and the health and social care professionals involved in the transition. It includes the associated distress when feeling unprepared. It incorporates concepts that contribute to the feelings of preparedness such as having adequate information and time to prepare to feel confident about either the decision to transfer to a facility, or confidence about the ability to provide appropriate care for the transition.

Stakeholders perspectives on preparing for the transition was discussed in five of the qualitative studies: by family carers in studies from Australia and the UK (Bauer et al., 2011; Fitzgerald et al., 2011; Emmett et al., 2014), by health and social care staff in an Australian study and a study from the US (Kable et al., 2015; Gilmore-Bykovskyi et al., 2017) and briefly mentioned in a study reporting the experience of people living with dementia from Australia (Digby et al., 2012). The degree of feeling prepared was closely related to the quality of communication exchanged between stakeholders.

For family members, being insufficiently prepared for being involved in discharge meetings undermined their ability to give an informed opinion about discharge decisions. Examples were given in a UK study where despite having regular contact with nurses, families were only informed about the extent of nursing care required for their relative at discharge meetings. This left them feeling discharge to a care facility was inevitable, a decision they felt unprepared for (Emmett et al., 2014). There were other examples of carers from an Australian study, families stated that the lack of communication relating to discharge arrangements left them feeling totally underprepared for their role, post hospital discharge (Bauer et al., 2011; Fitzgerald et al., 2011). An analysis of care records in a study from the US found a lack of patient and family carer education at discharge, the authors considered this could correlate to carers feeling unprepared for their role (Prusaczyk, et al., 2019).

The review also demonstrated that people living with dementia who were able to express their views also felt ill-prepared for the transition. People living with dementia involved in an Australian study were unable to recall the preparation involved in their transition but many admitted to feeling disorientated by the move (Digby et al., 2012). Nurses in a US study observed that people living with dementia were not sufficiently prepared for their transition from hospital to the nursing facility and said this contributed to a stressful experience for them. They reported examples where people thought they were being discharged home when in fact they were transferring to a care facility. They considered insufficient time was given for them to understand the decisions made (Gilmore-Bykovskyi et al., 2017).

Two studies found that health care professionals also felt unprepared for the transition from hospital to community facility which impacted on transitional care outcomes. In Australia and the US, the work of Kable et al. (2015) and Gilmore-Bykovskyi et al. (2017) found that pressure to react to the increase in hospital admissions meant that health care professionals felt additional pressure to discharge because the bed was required for the next admission. Nursing and medical staff expressed difficulties in formulating comprehensive discharge documentation as transfers to care facilities were being arranged quickly, with insufficient consultation. Nursing staff working in community care facilities reported there was too little time to prepare adequately, either in organising the environment and supplies such as ordering specialist equipment, comfort items or ensuring availability of medication. There were also examples of transfers after hours, late at night which was neither conducive for the person with dementia or the receiving care facility. All this militated against an optimal transitional experience.

The similarities of experiences across these three stakeholder groups are striking in that people living with dementia, families and health care professionals all reported that rapid decisions were made which resulted in insufficient time for family and people living with dementia to be fully involved in decision making about the transfer and for staff to adequately prepare all the necessary care arrangements. The three stakeholder groups described an unsatisfactory care experience.

2.4.2. Quality of communication

This theme is concerned with issues relating to oral and written communication. It mostly describes negative perceptions, however there were a few positive reports of when it worked well. It includes how families and people with dementia were communicated with about transitional care and their perceptions about the adequacy of this communication. The literature also raises communication of professionals working between hospitals and care settings and other community professionals as an issue impacting on transitional care. It also refers to written communication such as the information provided in care records which are used as communication tools for care continuity and the consequences of poor quality communication.

Only two studies did not mention communication (Kuluski et al., 2017; Gilmore-Bykovskyi et al., 2019). The remaining nine papers reported on the quality of communication. The quality of the communication between stakeholders was described as mostly inadequate.

Breakdown of communication between family members and the hospital were often reported in studies that sought the views of relatives. Family members participating in the study reported in two Australian papers (Bauer et al., 2011; Fitzgerald et al., 2011) described how care decisions about the person living with dementia were often based upon inadequate information. Additionally, the analysis by Bauer et al. (2011) found that family carers felt that they could be better informed about the discharge planning process and the follow up care after discharge. They also reported a lack of information about the options available to assist with decision making during discharge planning.

Conversely, a US study reported that people living with dementia or their family carers were usually involved in discussion about medication changes (Prusaczyk, et al., 2019). However, this study conducted a case record analysis and therefore relied on information being documented by health care professionals. Although health care professionals documented that the person and family had been involved in such discussions, it is impossible to know the adequacy of this interaction from this analysis.

From the healthcare professional perspective, Prusaczyk, et al. (2019) noted that people living with dementia were less likely than other patients to have complete medical information in their hospital care records. A qualitative study of nurse perspectives from the US (Gilmore-Bykovskyi, et al., 2017) similarly agreed that care decisions were often made based on insufficient information of health status, care needs, dementia related behavioural symptoms, and the social history of the patient. This proved difficult in areas such as individualised care planning, responding appropriately to the person with dementia and providing care continuity. This subsequently affected the experience of the quality of the transition for the person with dementia and or their family Additionally, Prusaczyk et al. (2019) highlighted a potential patient safety concern in care continuity, as they found most hospital discharge summaries they analysed were not received by the primary health care physicians.

It was considered that failures in communication could also affect the person’s ability to settle in the changed environment. Nurses participating in one study considered a lack of information could result in families thinking the nurse as inefficient and disorganised which could lead to a poor start to the care home experience for the person with dementia and their family. They considered this reflected badly on the care facility (Gilmore-Bykovskyi et al., 2017).

Studies from Australia, the UK and the US found that health and social care professionals often failed to communicate adequately with the person with dementia about discharge planning and outcomes (Digby et al., 2012; Emmett et al., 2014; Gilmore-Bykovskyi et al., 2017). In one study, case note analysis revealed that people living with dementia were significantly less likely to receive patient education from nurses about the in-hospital and after discharge care compared to those patients without dementia (Prusaczyk, et al., 2019). The authors considered a likely reason for this was the person was being moved to a care facility where an assumption was made that follow up care needs would be facilitated by other nursing staff.

Digby et al. (2012) who sought to hear the views of people living with dementia from one transitional care setting revealed they were often not consulted about their care and they felt powerless and unsettled in their new location. Emmett et al. (2014) also reported patients felt angry when excluded from decision-making about their future care needs.

However, communication was not always poor. In one study conducted in Australia both family carers and health and social care staff reported positive communication practice (Renehan et al., 2013). Six of the seven family carers who were interviewed felt they received adequate information, via regular meetings and contact with the Clinical Nurse Consultant prior to admission. This nurse conducted the assessments for the transitional care programme. Hospital nurses in this study considered face to face meetings with families during the stay and at point of discharge were beneficial to give information and discuss the programme. Although two of the seven families reported difficulty contacting the clinical nurse consultant, families appreciated having access to a named professional. Responses from social care professionals from the discharge destination facilities in this study were also favourable stating information was comprehensive and timely. Personalised documentation which detailed a full social and medical history of the person, was greatly valued by the facility staff.

To summarise agreement about the nature of communication was found across the studies and across the different stakeholders. Both family and health care professionals presented similar perspectives about the inadequacy of documented information about the person and their care information which were used by professionals to guide care and decisions. All stakeholders reported incidences of inadequate communication between health care professionals and the person living with dementia and/or their family. This was an important finding from the two studies who sought views from the person living with dementia. In one specific service there were positive communication experiences of health care professionals and families who received a specialised transitional care intervention designed to meet the needs of people living with dementia.

2.4.3. Inconsistency in quality of care

This theme is about the inconsistency in quality of care reported in the studies and its consequences. The reported inconsistencies in care varied from medication issues, care standards and the perceived competency of care professionals. Health care professionals also reported on the challenges they experience in caring for people living with dementia during this transition.

Studies from Australia, Canada and the US noted inconsistency in quality of care and in the limited capability and capacity of healthcare professionals to care for people living with dementia when transitioning to a different location. This often resulted in unsatisfactory experience and outcomes for all stakeholders (Bauer et al., 2011; Digby et al., 2012; Kable et al, 2015; Bloomer et al., 2016; Kuluski et al., 2017; Gilmore Bykovskyi et al. 2017; Prusaczyk et al., 2019; Gilmore Bykovskyi et al., 2019).

The experiences and outcomes of care for people living with dementia, were identified in the quantitative studies. Gilmore-Bykovskyi et al. (2019) found sudden changes in medication were common when the person transitioned from hospital to a skilled nursing facility. Changes in types of pain medications reportedly occurred. These changes also included an addition of pain medication in their discharge summary, medication they had not been prescribed during the last 48 hours of their hospital admission. They notably found that just under a quarter of their sample had pain medication discontinued at transition. The authors suggest such changes in medication regimes is highly likely to have a negative impact on the discomfort of people living with dementia when they transfer to a new setting.

In their study of transitional care interventions Prusaczyk et al. (2019) observed people living with dementia received fewer transitional care interventions compared to those without dementia, however several care interventions were noted for both groups. These included in hospital medication reconciliation, discharge planning, complete discharge summaries and cognitive screening.

People living with dementia interviewed in one study described a lack of understanding on the part of healthcare staff in the facility (Digby et al., 2012). They reported often feeling patronised and unsettled by the lack of personal empowerment in the environment. However, positive outcomes for people living with dementia who transferred into a specialist transition care programme in Australia were reported by staff (Renehan et al., 2013). In this study agitated behaviours were measured when the person with dementia was in hospital and then again when they had moved to the transitional care facility. Quantitative results indicated a reduction in the frequency of agitated behaviours on the Cohen Mansfield Behavioural inventory compared to the patient’s scores in hospital. Some of the data were incomplete here so some caution must be exercised with interpreting this finding. However, there was some qualitative verification, with families reporting reduction in agitation, improved socialisation and health outcomes following transfer from hospital to the facility.

Family care perspectives of quality of transitional care provided to people living with dementia was reported in three qualitative studies conducted in Australia and Canada (Bauer et al., 2011; Bloomer et al.,2016; Kuluski et al.,2017). Families participating in these studies expressed concern about the standards of care in hospitals. In particular, they described assumptions were made about the patient's psychosocial needs, their level of function, (such as maintaining activities of daily living whilst in hospital) and family involvement.

In two studies healthcare professionals' perspectives on provision of care focused on the difficulties they or other staff encountered in providing quality care (Kable et al., 2015 Gilmore-Bykovskyi et al., 2017). Care facility and hospital healthcare professionals taking part in an Australian study reported difficulties in caring for people living with dementia particularly those with behavioural symptoms (Kable et al., 2015). Care home staff stated that people living with dementia often returned from hospital over-sedated, without having their original health needs addressed. They attributed this to hospital-based healthcare professionals' inability to respond to the needs of the person living with dementia. Hospital based nurses in turn felt they lacked knowledge in caring for people living with dementia and felt specialist support was lacking. Additionally, hospital physicians said nurses would often ask for medication in managing the behavioural and psychological symptoms of dementia.

Challenges about supporting people living with dementia who are discharged from hospital were also reported. Nurses working in skilled nursing facilities in the US admitted to feeling ill-equipped to care for people living with dementia recently transferred from hospital (Gilmore-Bykovskyi et al., 2017). They attributed this to the lack of detailed information about the person's behaviour and the supportive care required to provide an individualised approach. The work of Kable et al. (2015) in Australia found that care facility nurses felt that hospitals under reported behavioural symptoms. As a result, the care facility did not have the workforce capacity to respond appropriately to some of the needs of patients transferred from hospital. Additionally, care home staff in this study reported that when transfers happened during out of office hours, there was frequently no registered nurse on duty.

Positive outcomes of care were reported by families and health care professionals in one dementia specific transitional care programme (Renehan et al., 2013). However, there was consensus noted across all stakeholders participating in the other studies of inconsistencies in care when the person with dementia was to be discharged from hospital and move to a community care setting. The lack of competency or understanding of the needs of people living with dementia of some health and social care staff was commonly reported by families, people living with dementia and the health care professionals.

2.4.4. Carer engagement and roles of the family

This theme is about the fundamental role that families and carers reportedly had in helping to facilitate a successful transition. The extent of family engagement is discussed. The stress associated with inadequate family engagement, making decisions and its impact is highlighted.

All stakeholders agreed that families have an important role to play in transitions from hospitals to care facilities. All but one of the studies (Gilmore- Bykovskyi et al., 2019) discussed this topic.

Studies from the UK, Australia and Canada found that families' experiences' including them supporting the care of their relative which were often due to inadequacies in the care system. Family members reported they were actively involved in providing advocacy, facilitating communication, helping with personal care, providing stimulation and helping to prepare the environment (Emmett et al., 2014; Bloomer et al., 2016; Kuluski et al., 2017). Despite this recognition of the valuable role played by families, Bauer et al. (2011) and Kable et al. (2015) found that were often not consulted about discharge arrangements. In the work of Prusaczyk et al. (2019) it was found families were less likely to be included in carer education about follow up needs. The lack of family involvement and exclusion in decision making led family members to feel frustrated and unappreciated (Emmett et al., (2014).

Prusaczyk, et al. (2019) found from their analysis that moving from hospital to care home for the first time occurred more frequently for people living with dementia. This process can be particularly challenging for family members. Families reported tension and family conflict about care decisions (Bloomer et al., 2016). Conflicts of interests between patients and relatives regarding funding ongoing care were also noted in a UK study (Emmett et al., 2014). Family carers in three studies experienced the time leading up to discharge within the hospital environment and the associated decision making about moving into a care facility as challenging. They found the care processes and systems, such as the speed in which decisions were made to move the person, was particularly stressful (Bauer et al., 2011; Fitzgerald et al., 2011; Emmett et al., 2014; Bloomer et al., 2016).

From the perspectives of people living with dementia, both Fitzgerald et al. (2011) and Digby et al. (2012) reinforced that family support and regular presence provided comfort to the person living with dementia.

Health care professional perspectives included both positive and negative experiences of working with families. Nurses working in skilled nursing facilities said they appreciated the opportunity to work directly with families in preparing the person for transfer to the facility as they believed this helped to facilitate smoother transitions (Gilmore-Bykovskyi et al., 2017).

Healthcare professionals in one study also reported working with families was sometimes difficult, with hospital nurses stating supporting families was a challenge, due to their multiple roles (Renehan et al., 2013).

Health care professionals, people living with dementia and their families had similar perspectives in that successful transitions occurred when family members were involved prior, during and after the transfer. However, relatives that were interviewed expressed that they are frequently not fully involved in the transitional care decisions and processes of care.

2.5. Discussion

In this section I will summarise the key findings from this review:

- the paucity of research on care transitions for people living with dementia transferring between hospitals to care facilities, particularly in the UK
- people living with dementia often move into care facilities for the first time following a hospital admission
- four key elements of transitional care that are important for successful transitions
- clinical implications for practice improvement
- the nurses' role in providing care at this transition
- the need for further research on transitional care between hospital and care homes for those living with dementia.

2.5.1. Paucity of research.

It is believed this is the first review of stakeholder's perspectives on the transition for people living with dementia from hospital to community care settings. A striking finding was the paucity of studies (n=10, from 11 papers) eliciting stakeholders' perspectives on these experiences and outcomes of care. Eight of the ten studies were rated high quality. Most of the identified studies were conducted in Australia and relatively recently from 2011. Despite the development of the concept of transitional care in the US, only three US studies on transitional care examine stakeholder perspectives of this transition for those living with dementia. Additionally, it appears to be an under researched topic in the UK with only one study (Emmett, et al., 2014) identified for this review. This suggests research of transitional care between these care settings for people living with dementia has not been a priority in the UK.

2.5.2. Moving to a care facility for the first time from hospital

Evidence from this review supports findings from other studies that many people living with dementia move into a community care facility for the first time from hospital (Audit commission, 2011, Callahan et al., 2015, Harrison et al., 2017). This can be for either long-term care or as an alternative setting for either rehabilitation or to wait until a long-term care placement is found. Moving to alternative settings can have clinical implications, as opinion is mixed whether multiple relocations for people with dementia causes further problems and should be minimised (Mortenson and Bishop, 2016). However, best practice recommendations in the UK also highlight those decisions for long term care should not be made when a person is in crisis (NICE, 2015). Arguably, a period of time in a sub-acute or similar facility after a hospital admission may help to address this. It identifies a need for greater clarity within policy about potential multiple relocations and the impact of this on transitional care for people living with dementia.

2.5.3. Four key elements of transitional care

Although previous reviews have focused on hospital discharge processes for people living with dementia (Chenoweth et al., 2015, Mockford, 2015, Stockwell-Smith et al., 2018), the present review examined additional transitional care activities with emphasis on moving to and being received by a care facility. Findings from this review are consistent with the earlier reviews, in identifying some of the barriers to successful transition out of hospital for people living with dementia. This review further highlights specific issues relating to transferring to a care facility. Four inter-related themes were identified which were important to all stakeholders: adequate and inclusive preparation for transition, the need for good quality and timely communication, quality of care which meets the needs of people living with dementia and active family carer engagement.

2.5.4. Clinical implications for practice improvement

Studies in this review highlight several clinical practice implications resulting in unsatisfactory experiences, which could be improved. Whilst experiencing an alternative location in care or waiting for placement, the person with dementia and their family reported receiving care that did not meet their needs. Family members frequently acted as advocates and provided ‘hands on’ care whilst the person was in hospital or a transition setting but conversely were not included in decision making about care. These findings are also reflected in a review of proxy decision-making by families of people living with dementia, which noted family carers were frequently excluded from decisions made in hospital (Lord et al., 2015). Furthermore, this review of stakeholder perspectives of transitional care between hospital and care facilities identifies the marginalisation of the person living with dementia, who were infrequently included as active participants in the transitional care process or associated decision making. A recent study using case note analysis also revealed that people living with dementia were frequently not consulted about their care decisions (Rhynas et al., 2018). This supports a need for nurses and other health care professionals to facilitate greater involvement of the person living with dementia and their family.

Some health and social care professionals reported they did not have the skills to manage the complexities involved in caring for people with dementia. It is commonly recognised that when people with dementia are unwell or are somewhere unfamiliar, their response may be one of heightened anxiety and agitation (Tew Jr, 2012) yet examples were given of hospital-based nurses being unable to respond with non-pharmacological approaches and relying on medication. This is not unusual. In a literature review conducted by Digby et al. (2017), the care of people living with dementia in hospital was reported as task orientated, delivered with little social engagement and sometimes with a lack of compassion. Inappropriate responses to agitated behaviours such as the use of security services were also highlighted. Despite an increased focus on improving the training and competency of acute care staff in caring for people living with dementia (NHS, 2018), there is a dearth of literature reporting an improved level of dementia care skills of acute care staff. Given that this review has identified many people living with dementia often receive short-term care due to delays in arranging care to their final destination, it is important that nursing staff in these areas have the skills to provide competent care.

Evidence from this review supports findings from another review of hospital discharge (Chenoweth et al., 2015) with respect to patient safety and continuity of care. This relates to poor transfer of information between settings or primary care physicians who also have a responsibility for follow up. The present review of transitional care between hospital and community care facilities identified people living with dementia experienced gaps in pain control on transfer or abrupt changes in their pain management regimes. Sudden changes in medication regimes at transfer were also reported in another study concerning older people in a transition between hospital and a skilled nursing facility (King et al., 2013). System pressures resulting in sudden transfers were cited as a barrier to providing sufficient information which impacted the ability of nurses to provide person centred care. This review identifies the importance of nurses requiring a complete medical and social history in order to respond appropriately to the needs of people living with dementia, however this was often lacking. This was also revealed in King et al.'s (2013) study who reported nurses working in a skilled nursing facility spent a lot of time reconciling missing patient related information when a person transfers from hospital. This suggests there is a need for health and social care systems to work collaboratively to address concerns about abrupt changes in treatment before transfer and improving the sharing of personalised patient information.

Assumptions were made by hospital-based nurses and medical staff that nurses working in community care facilities could respond quickly with little appreciation of the time required in preparing the right environment and arranging supplies of essential medication. Similar findings were noted in a Swedish study (Kirsebom et al., 2013) that examined hospital and care home nurses' views of older people transfers between settings. It found that transfers back to care homes were commonly done with limited planning, late in the day with little communication between nurses in either setting. This study is significant as it examined both hospital and care home nurse perspectives, only two of the studies in this review examined perspectives of professionals working in the hospital and the community care facilities. None of these studies were conducted in the UK, which demonstrates again the need to understand both perspectives in the UK.

Furthermore, the emphasis on rapid turnover of hospital patients is also not conducive to the person living with dementia. Kitwood's theory of person-centred dementia care and the need to prevent behaviours such as outpacing and de-personalised care regimes suggests that such hurried transfers with little preparation of the person can significantly undermine well-being (Kitwood, 1997). System pressures also place staff under considerable stress. Findings of this review echo those in an English study (Connolly et al., 2009), who reported practitioners were conflicted by competing internal and external pressures, which undermined their professionalism, caused frustration, and resulted in de-personalisation of care. The findings from this review show how discharge activities are implemented can have unintended consequences for the care the person receives at the care facility.

2.5.5. Nurses’ role in providing care at this transition

Only four studies investigated perspectives of health care professionals which shows how seldom their voice is heard in transitional care research. The most frequently represented health care professional group in the study samples was nurses. Findings support the existing policy emphasis and research evidence that nurses have a fundamental role in providing transitional care, sometimes multiple roles (Renehan et al., 2013). Engaging with family was a key role and successful transfers were reported when nurses were able to effectively engage with families prior and throughout the transfer (Renehan et al., 2013; Gilmore-Bykovskyi, et al., 2017). Increased family satisfaction was also achieved when families had a named nurse with whom they could liaise and communicate with both in the hospital and following transition into the facility (Renehan et al., 2013). The practice of having a dedicated professional responsible for discharge planning is also supported in national UK guidance but is not specifically about their role after transition (NICE, 2015).

2.5.6. Further research on transitional care between hospital and care homes for those living with dementia

Findings from this review suggest transitional care of people already living in a care facility who are admitted to hospital and return to their care home is an underdeveloped area of research. Only two studies in this review reported data on this pathway (Kable, et al., 2015; Prusaczyk, et al., 2019). Additionally, systems and processes between settings appear to be in conflict. An appreciation of perspectives of both ends of the pathway, and a focus on working together may help to facilitate better transitional care experiences. This along with the lack of UK evidence on care transitions for people living with dementia emphasises there is now a compelling argument to conduct further research in this area in the UK.

2.6. Limitations of the included studies

There are some limitations of this review which need to be considered when interpreting the findings. The qualitative studies reviewed here used few methods of data collection, mostly focus groups and interviews. Although these methods yield rich data, the researchers are relying solely on the interpretation of the participants. Only two studies used supplementary data collection methods. Observational methods were particularly lacking, and one of the reasons may be the practicality of being able to observe transitional care in practice. Most studies used convenience sampling, relying on volunteers with certain experience to come forward to participate in research, their views may not represent those who did not volunteer and may be skewed due to having negative experiences of the transition. The two quantitative studies both focused on analysing care records. Accuracy of records cannot be guaranteed, in the case of examining transitional care interventions, care details may not have been recorded. In the study by Gilmore-Bykovskyi et al. (2019) investigating medication prescribing patterns, patient level conditions were not addressed to establish prescribing decisions. A further limitation of all studies is the diversity in care facilities. There were a range of providers studied from several countries and different health care systems including academic hospital institutions, community hospitals, government funded, privately owned profit and non-profit facilities. Operational and clinical procedures, staff ratios and training are likely to be varied. Their findings may not be transferable to other healthcare contexts.

2.7. Limitations of this review

Although a comprehensive search was undertaken from six databases and additional hand-searching, only ten studies (11 papers) were identified. More studies from grey literature and non-peer reviewed journals may exist, but not necessarily of high quality. Additionally, there may be relevant studies in languages other than English. This limits the conclusions that can be drawn.

2.8. Literature review conclusion

What was known prior to the review

Prior to undertaking this review, I presented evidence that the transitional care of older people moving out of hospital to care homes was fraught with clinical care concerns. I highlighted those studies about transitional care are often focussed on measuring clinical and cost effectiveness rather than stakeholder experiences. I identified that key elements of transitional care which aim to improve the care experience of older people transferring out of hospital and back home had been developed. I also established that nurses are key professionals in providing these elements of care. Studies, some of which were not peer reviewed had indicated people living with dementia may have additional vulnerabilities and specific needs which may require an adaptation of these key elements of effective transitional care.

What this review has found

This key transition from hospital to community care facilities for people living with dementia is an under researched area, particularly in the UK. It presents findings from peer-reviewed studies that the care that people living with dementia receive, when they transition between hospital and community care settings including care homes, is variable in quality and a significant healthcare problem.

The review identifies that diverse stakeholders, people living with dementia, their family carers and health and social care professionals agree on the key elements of quality of care which are needed for people living with dementia who move from hospital to community care facilities. They share common views that adequate preparation for transfer, effective communication between settings and stakeholders, quality care whilst their long-term care needs are arranged and family engagement throughout are required for the effective transition from acute care to a community facility.

This review supports findings from other studies that nurses have central roles to play in providing transitional care in terms of communicating information across the care settings and coordinating continuity of care with other professionals and families. The review has identified emerging findings of the nurse perspective on the barriers to quality transitions for people living with dementia. These were poor quality information at transfer, inadequate time and information to prepare the person with dementia for transfer which affected nurses' ability to provide quality individualised care.

The review has confirmed that despite large numbers of people living with dementia living in care homes who are frequent users of hospital services, there is a lack of investigative work on transitional care in this context, people living with dementia and transitions to care homes following a hospital stay.

The specific gaps in the body of knowledge this PhD study will address

The results of this review and other evidence raised in chapter one confirms that knowledge is insufficient in the following areas:

1. The extent of the nurses' role in the transitional care of people living with dementia who return to their care home after a hospital stay.
2. The UK nurses' perspective, both the hospital-based nurse and nurses based in care homes on what optimises care at this transition (only one UK study was found in the review)
3. Whether the components of effective transitional care cited as best practice are aligned with that of the care nurses provide at transition.

I believe there is now a compelling argument for exploring both hospital and care home nurse perspectives in providing optimal care for people living with dementia who move between hospital and care home settings in the UK. In this next section I will present my study aims and research questions.

2.9. Research aims and questions

2.9.1. Research aim

This PhD aims to explore hospital and care home nurses' perspectives on how they optimise care for people living with dementia who transfer from hospital back to their care home, and the extent to which the care they provide aligns to best practice.

2.9.2. Research questions

1. How do hospital and care home nurses describe their role in providing care for people living with dementia who are returning to their care home after a hospital stay?
2. What are the facilitators for optimising nursing care for people living with dementia returning to their care home from hospital?
3. Does the care provided by hospital and care home nurses, align to best practice guidance, the components of effective transitional care, as identified by Naylor et al. (2017)?

2.10. Chapter conclusion

In this chapter I have detailed the process adopted for undertaking a systematic literature review and appraised the evidence about the stakeholder perspectives of care for people living with dementia who move from hospital to community care facilities. I have established a gap in the UK literature, and I have argued why this research problem warrants investigation. I have introduced my study outlining the research aims and questions. In chapter three I will introduce and explain the underpinning philosophical perspective I adopted, and the methodology used in the design of my study.

Chapter Three: Research paradigm

3.1. Introduction

The overall of aim of this study is to explore hospital and care home nurses' perspectives on how they optimise care for people living with dementia who transfer back to their care home after a hospital stay. In this chapter I present the research paradigm which underpins this study. A paradigm can be described as an over-arching framework that consists of ideas, beliefs, opinions and values (also known as ontology, epistemology, methodology), which guide the researcher to carry out a study (Harvey and Land, 2017). I start by defining these terms and discuss alternative paradigms that I considered but rejected. I provide an overview of realism with a focus on critical realism, its origins, and my rationale for adopting it. I then discuss methodologies which are appropriate to use within this paradigm. I give a brief overview of the alternative methodologies which were considered and the need for reflexivity when using a qualitative methodology. I introduce and provide a rationale for the one I adopted: qualitative descriptive methodology.

3.2. Defining research terms

Crotty (1998: 2) states that in developing a process to create knowledge the researcher must substantiate their choice, which involves examining their underlying assumptions about reality and what they bring to their work. He purports the four basic elements of any research process are:

1. What methods are proposed? (The techniques used to gather and analyse data)
2. What methodology steers the choice and use of the methods? (The strategy/design)
3. What theoretical perspective lies behind the methodology? (The philosophical stance informing the methodology)
4. What epistemology and ontology informs the theoretical perspective? (The beliefs about the nature of being and reality, and the theory of and generation of knowledge embedded in the theoretical perspective) (Crotty, 1998: 2).

3.3. Alternative paradigms

Healthcare research has a long history of positivism, often involving medically dominant experimental studies (Harvey and Land, 2017). This paradigm values objectivity in the search for knowledge requiring objective measurement using quantitative methods (Weaver and Olson, 2006). Interpretivism as an alternative argues that truth consists of multiple realities that are subjectively perceived by individuals (Denzin and Lincoln, 2018). Interpretivists argue that the generation of knowledge is obtained by understanding the perspective of individuals in the context in which they happen (Denzin and Lincoln, 2018).

My study aims to explore hospital and care home nurses' perspectives on how they optimise care for people living with dementia when they move from an acute hospital to their care home setting. I propose to do this by asking them to describe their role. A reasonable proposal would be to use the interpretivist paradigm as the aims of the research fit with the ontological and epistemological beliefs that individuals construct their own understanding of reality and knowledge is generated from a shared understanding. However, as a nurse myself, I also have an interest in practice development. I was additionally keen to find out about any facilitators that optimise the implementation of nursing care in this transition. This is one of my research questions. This would mean investigating the mechanisms that have an influence on the actions nurses take. This study focus therefore takes me beyond the realms of interpretivism as it also seeks to explain causal factors Delanty (1997) cited in (Wilson and McCormack, 2006). This led me to consider incorporating realism as my primary research paradigm.

3.4. Realism

Realism is an alternative view of positivism and interpretivism and offers a different approach to understanding reality (Williams et al., 2017). It accepts the real world has multi-layers of complexity and is concerned with why and how events occur and that events can be explained even if they were not foreseen (House 1991, cited in Robson and McCartan, 2016: 31). The realist view of science is to gain knowledge of events, structures, mechanisms and discover theories to explain the real world (Schiller, 2016). The process of clarification is done via abduction or retroduction which means inferences are made by investigating patterns to provide plausible explanations of events in the context of multiple hypotheses (Robson and McCartan, 2016).

3.4.1. Critical realism

A version of realism, critical realism emerged in the 1970s and 1980s primarily through the work of Bhaskar and is now becoming a popular research paradigm, as it gives a detailed account of its ontology and epistemology (Fletcher, 2017). It begins with an ontology which utilises a stratified model to differentiate between three layers of knowledge: ‘real’, the ‘actual’, and the ‘empirical’ (Schiller, 2015). Fletcher (2017: 183) uses the metaphor of an iceberg to describe these three levels but emphasises the levels are not separate from each other and can interact. The first (the tip which is visible) is the empirical level, which is experienced and observed events, understood through human interpretation. The second (the water level at the point the ice becomes emerged) is the actual level; events occur whether observed or not and can be different from what is observed at the empirical level. The third is the real level, (the ice that submerged in the water) this is where causal mechanisms within objects or structures cause events at the empirical level to occur. The objective of critical realism is to explain social events by identifying these causal mechanisms and the effects they can have throughout the three layers.

Critical realism is therefore concerned with causality and focuses on the interface between ‘agency,’ what determines how people act and ‘structure’, the circumstances which influence agency (Williams et al., 2017). There is an interest in identifying and understanding people’s responses to different resources within complex social situations (Williams et al., 2017) and to understand the influencing factors, e.g., culture, power and relationships, that exist underneath the surface (McEvoy and Richards, 2003). Critical realism acknowledges there is a flux of events caused by the inter-play of these different mechanisms and that causal explanations cannot always be fully determined. Inferences are made but do not necessarily entail conclusions (Downward et al., 2002).

Health care interventions are complex. Pawsey et.al (2005) describe them as theories, often based on hypothesis that if they are applied in a particular way it should result in an improved outcome. They posit these effects are achieved by the input of individuals for example, healthcare professionals. However, they acknowledge there can be human fallibility or that a series of events may not occur as planned which can lead to unintended outcomes. By applying critical realism researchers are seeking to understand and explain the mechanisms and contexts which may influence the outcomes of health care interventions

In gaining this understanding these researchers analyse their data using a variety of approaches. Inductive and deductive methods can be used but abduction and retroduction are also emphasised (Vincent and O'Mahoney 2018. Abduction or abductive reasoning has been described as a process which requires the researcher to "interpret and recontextualise individual phenomena within a conceptual framework or a set of ideas" (Eastwood et.al. 2014:3) and can done by combining observations (Interviews) with application of theory (Vincent and O'Mahoney 2018. Meyer and Lunnay (2013) discuss abduction in some length and state abduction as being complementary to deduction. They highlight as deduction aims to prove or disprove a theory it can mean findings are not analysed if they do not fit the theoretical framework. They posit abduction involves analysing data which falls outside of the theoretical frame and is a way of discovering circumstances or structures which might not be obvious. Abduction is therefore the movement from events to their causes (Clark, 2008).

Critical realism is a highly relevant philosophy to be used in healthcare research. For example, it can be used to make practical policy recommendations to address social problems (Fletcher, 2017). It can also be instrumental in nursing, as barriers and facilitators within the care environment need to be understood if evidence-based interventions are to be effectively implemented (McEvoy and Richards, 2003)

3.4.1.1. Application of critical realism

In my study I want to explore nurse perspectives of providing transitional care of people living with dementia when they move from an acute hospital to their care home setting. I would like to ask nurses to describe their role in both settings, and to explore the context and influencing factors which optimise care and as such it lends itself to a critical realism philosophical perspective. The focus of this perspective is to understand complex social situations and generate knowledge from this understanding. Transitional care is a complex activity as multi-components of care are involved. As identified in chapter one transitional care has been extensively studied, albeit not with care home residents living with dementia, but frameworks derived from US studies already exist for recommended transitional care components. It is therefore possible to hypothesise what transitional care should consist of. I intend to use one of these frameworks to gain further understanding about the transitional care provided by hospital and care home nurses.

My study draws a sample of nurses from two complex care environments, hospitals and care homes. There are likely to be system-level factors such as capacity and demand, organisational procedures, legislation and individual influences such as human interaction which may influence how nurses perform their role in providing transitional care and with a consequent impact on the outcomes of care. Furthermore, we know transitions can be challenging for people living with dementia because a change in locations of care when someone has compromised cognition and understanding can bring about anxiety (Tew Jr, 2012). This may also have a bearing on health status and add to the complexity of transitional care needs.

There are likely to be multi-layers of complexity in implementing transitional care for people living with dementia who move between these two settings. Given the dearth of research here, furthering understanding of nurses' perspectives of their role in providing care and the causal factors that influence that care would be an essential addition to the literature. Additionally, understanding if their care aligns to recommended transitional care practice, will aid our understanding about whether such frameworks are applicable in this context or may need modification. Investigating the phenomena in this way could potentially contribute to the evidence base of how nursing care can be developed and improved for people living with dementia who transfer between these two settings.

By interviewing nurses, I will be investigating in depth the three layers of knowledge; by listening and recording their perceptions and interpretations of their role in providing transitional care (the empirical level); by asking about transitional care, I am examining the transitional care events that take place when a care home resident living with dementia transfers from hospital to their care home (the actual level); trying to understand the factors that influence optimal care and in doing so will be investigating the context, challenges and facilitators for transitional care (the real level). I will analyse these data using a combination of induction, deduction and abduction. I will use induction to examine what is said in the interviews but will use the care component framework by Naylor et al (2017) deductively as a theoretical framework for understanding if their care aligns to this best practice. I will be analysing data that may not fit within the theoretical framework and be examining data about causal factors. Using abductive reasoning, plausible inferences and explanations will be made about the causal factors that influence the role of the nurse in providing optimal transitional care to care home residents living with dementia.

3.5. Methodologies considered within the critical realism perspective

In this section I present the methodologies (research designs) which I considered for my study. As critical realism does not wholly reject the positivist and interpretivist paradigms, and merely offers an alternative, it embraces both qualitative and quantitative methodologies. To explore nurse perceptions of providing transitional care, I selected a qualitative design. I now explain qualitative methodologies and the various alternatives which were considered and my rationale for choosing descriptive qualitative methodology.

3.5.1. Qualitative methodologies

Qualitative methodologies are often used in health care research because they are useful for exploring individual narratives, understanding the context of the problem and any causal factors, developing theories, and when quantitative measurement is deemed unsuitable for the problem (Creswell and Poth, 2018). It is commonly acknowledged there is a degree of subjectivity associated with using qualitative approaches, as the researchers are often close to their research and therefore qualitative researchers must use reflexivity, a critical form of self-reflection on the research process and the interpretation of the findings (Topping, 2015). This point is significant as in my case I am undertaking research into my own profession. I provide a section on reflexivity in chapter four when discussing the methods I used to conduct my research. There are five common qualitative methodologies: narrative, grounded theory, phenomenology, ethnography and case study (Creswell and Poth, 2018). I will now describe each of these and provide a rationale for why I did not select them.

3.5.2. Alternative qualitative methodologies considered

3.5.2.1 Narrative methodology

Narrative methodology is mainly focused on in-depth individual stories, often with small numbers of people and is a useful approach understanding experiences of seldom heard voices or experiences of health and illness (Freshwater and Holloway, 2015). Although it has been used to understand the professional practice of nurses (Kelly and Howie, 2007), I did not consider it appropriate for my study. Narrative explorations are often extended accounts of people’s lives achieved over periods of time (Reissman and Quinney (2005) cited in Robson and McCartan, 2016) and I considered it may have been problematic to release nursing staff to obtain such in depth stories. Furthermore, my study had a narrower focus on exploring nurse perceptions of providing transitional care, in describing their role rather than exploring wider life experience.

3.5.2.2. Phenomenological research

I also ruled out using phenomenological research early in the planning stages of my study. This is an appropriate methodology to select if I had been investigating the lived experience of the transition as experienced by the person living with dementia or their family members. It uses a highly interpretive method, in that the researcher seeks to understand concealed meanings to understand the world of the individual (Robson and McCartan, 2016). It can be very useful in nursing to provide nurses with knowledge about such experiences of illness or care, which in turn may help to support the delivery of person-centred care (Galvin and Holloway, 2015). My aim was not to investigate the meaning of the lived experience as such but to obtain a description of nurse roles in transitional care, from their perspective and identify the facilitators for optimising transitional care.

3.5.2.3. Grounded theory

Grounded theory was considered, as this methodology is concerned with developing new theories or frameworks. Cresswell and Poth (2018) advocates its use if frameworks are available but were developed for different populations. It could be argued that my proposed use of care component best practice guidance, developed for care transitions from hospital to home, in this study to answer my third research question could apply here. This research question is focused on exploring this best practice guidance to establish if nursing care is aligned with it and that the guidance applies to hospital to care home transitions**.** However, adapting this guidance was not my primary focus, the main focus of my study was to explore nurses' perceptions of providing care by asking nurses to describe their role in both of these care settings, and to explore the facilitators which optimise care. The application of the guidance would be used to analyse the collected data in order to explore if nurses' roles aligned with this best practice and if it could be adapted for this transition.

Additionally, in grounded theory the researcher sets aside their previous knowledge and ideas so that an analytical theory can develop from the data (Cresswell and Poth 2018). I considered this may be a challenge to me as, not only did I possess a working knowledge of the nursing role, I had also read extensively around the topic prior to planning the study. Some grounded theorists do not advise extensive reading of the literature prior to embarking on a study as the influence of other studies may affect data collection and there is a risk of not being open to emergence of new categories (Glaser and Holton, 2007).

3.5.2.4. Ethnography

Ethnography was ruled out for pragmatic reasons. Ethnography involves the researcher studying a culture or a social group, in particular the behaviours interactions, and feelings that are experienced by the culture sharing group (Holloway and Galvin, 2015). This involves the researcher spending long periods of time with research participants observing how they interact in order to understand the meaning of their interactions and the culture of their group (Creswell and Poth, 2018). As a single researcher this would have been too time-intensive for my project, limiting the number of hospital and care home settings used. It was considered it might be practically difficult to plan observational work to ensure actual care transitions between care settings could be witnessed.

3.5.2.5. Case study research

Case study research initially appeared a relevant approach for my interest in exploring nurse perceptions of providing transitional care. The case study method is a common approach to study healthcare and there has been an increased use within nursing research (Anthony and Jack, 2009). There have been several operational definitions and after a review of definitions Simons (2009: 21) developed one to include the purpose and research focus.

"*an in-depth exploration of multiple perspectives of the complexity and uniqueness of a particular project, policy, institution programme or system in a real-life context. [ ]. The primary purpose is to generate in depth understanding of a specific topic to generate knowledge and or inform policy development, professional practice…"*

My study topic could lend itself to a case study approach. The project aim in exploring nurse perceptions of providing transitional care would generate knowledge about nurses' roles in transitional care for a distinct client group, care home residents living with dementia who transition from hospital back to their care home. However, one of the difficulties in case study research is defining the case (Creswell and Poth, 2018). The more I read into this approach I realised the complexity of case definition. I considered nurses being the 'case' both those working in hospitals and those in care homes, as two distinct cases. Another option was to consider the 'person living with dementia undergoing the transitional care process' the case, therefore investigating specific cases of care home residents and examining the role of the nurse in providing care. Although these were possibilities, I decided to explore other methodologies.

3.5.3. Consideration of alternative quantitative methodology or mixed methods

As a critical realism paradigm is inclusive of a mixed methods study strategy, I considered this option. Here I describe my deliberation about using a survey research design.

3.5.3. Survey research

Surveys can be useful to gain opinions and beliefs about an issue from a large group of people (Fink, 2006). Survey research can be both quantitative and qualitative in design, in that either or both questionnaires and interviews can be used as data collection tools (Robson and McCartan, 2016). I considered using a national questionnaire-based survey to ascertain nurse perception of providing transitional care and explore their role. A reservation for progressing with this were potential drawbacks such as poor response rates affecting non-response bias (opinions of those who do not respond may differ from that that do) which is a common issue. This can affect generalisability of findings (Jones and Rattray, 2015). I also considered a survey would not yield such rich data to enable a full exploration of nurse perceptions in providing transitional care and exploring the facilitators for optimising care.

3.6. Selected methodology: Descriptive qualitative methodology

In this section I give an overview of descriptive qualitative methodology, the strengths and weaknesses of the approach and why I have selected it as the methodology for my study.

When the research questions do not fit within the boundaries of the established qualitative methodologies as previously described, they are often known as generic qualitative research studies (Kahlke, 2014). Descriptive qualitative methodology is one of these generic approaches which is championed by Sandelowski (2000; 2010). In her seminal papers she noted researchers conducting descriptive methodology but labelling it as one of the common five qualitative approaches, if it had nuances of that methodology. Her papers purports that ‘basic’ or ‘fundamental’ description is worthy of its own methodology and should be differentiated and respected alongside other methodologies (Sandelowski, 2000: 333).

A methodology should be dependent upon the nature of the enquiry and descriptive qualitative methodology should be chosen when low inference interpretation is required (Sandelowski, 2000). Low inference is when researchers report findings with minimal assumptions or ideas about what the evidence means (Silverman and Marvasti, 2008). Sandelowski (2000: 333) recommends researchers stay ‘close to the data’ as this increases the likelihood of agreement amongst researchers of what is described and increases the validity of the data. She argues staying close to the data does not make this a superficial methodology, and emphasises that researchers must still analyse and interpret their data, by looking at ‘what is into, between, over and beyond text’ (Sandelowski, 2010:78). She stresses reporting facts, and the meanings participants give to those facts is not easy, but by doing this accurately a comprehensive summary of events can be articulated.

Criticism of this approach includes the fact that there is no prescribed underpinning theory (Kahlke, 2014). Sandelowski (2010) argues that although descriptive qualitative methodology is less theory driven, she acknowledges that researchers approach their study with some bias. Using the lens of a theory or conceptual framework to guide the study is permissible. The difference is researchers are not bound by it and can move away if appropriate to the study (Colorafi and Evans, 2016).

Well-designed research should demonstrate a link between epistemological, theoretical, methodological and methods framework (Crotty, 1998). Yet critics of descriptive qualitative methodology argue there is a potential for studies to lack congruence between these four elements (Kahlke, 2014). Kahlke (2014) argues that generic qualitative methodologies actually support that the methodology and methods are informed by the question and not the other way around. In my case, my first research question asks for a description of the nurses' role in transitional care and therefore requires a methodology that facilitates that description. Descriptive qualitative methodology offers flexibility of methods for sampling, data collection and analysis: Focus groups, interviews and content analysis are commonly used (Colorafi and Evans, 2016).

This methodology fits my study. Descriptive qualitative studies have previously been conducted using a critical realist perspective (Leung and Chung, 2019). These authors argue that this methodology and philosophical perspective are compatible because it facilitates access of different types of knowledge. According to Leung and Chang (2019) content analysis often the method used in qualitative description is drawn from manifest (descriptive level) and latent (underlying meaning) content and applying critical realism to direct analysis gains access to causal explanations about phenomena. This they believe makes findings more useful particularly in the health care context and when investigating efficacy of interventions.

In order to obtain a full exploration of care home and hospital nurses' perceptions in providing care to people living with dementia who transfer between hospital and their care home, there would be a requirement to stay 'close to the data' to ensure their perceptions were accurately reported. Adopting a critical realist perspective, will additionally facilitate detailed exploration of the perceived consequences and outcomes of transitional care, identify what influences optimal care and why. The use of a theoretical frameworks to understand phenomena is permitted in both critical realism and in qualitative descriptive methodology and therefore they are compatible with all my research questions.

3.7. Chapter conclusion

This chapter describes the methodological and epistemological underpinning for the aims of my study, critical realism. I have demonstrated this paradigm fits with my own interest of practice development and gaining an in depth understanding of the facilitators for optimising care, in this case transitional care. I have argued my selection of qualitative descriptive methodology as described by Sandelowski (2000; 2010) as an appropriate methodology to use in my exploration of nurse perceptions of providing transitional care and I have provided a rationale as to why other methodologies were not selected. The methods selected which are comprehensively discussed in the next chapter are compatible with this methodology as described by Sandelowski (2000) when she championed this as a distinct qualitative methodology.

Chapter 4: Methods

4.1. Introduction

At the end of the literature review in chapter two, I identified that the transition from hospital to care homes for people living with dementia was an under researched area in the UK. No UK studies were identified in the review that explored the transition for care home residents who were admitted to hospital and returned to their care home. I also identified a gap in the literature about nurses' perspectives of this transition in the UK. Given nurses' key role in providing transitional care, the aims of my study are to explore nurse perspectives on how they optimise care for people living with dementia when they return to their care home after a hospital stay and the extent to which the care they provide aligns to best practice. Therefore, my study is focused on addressing three research questions: 1) How do hospital and care home nurses describe their role in providing care for people living with dementia who are returning to their care home after a hospital stay? 2) What are the facilitators for optimising nursing care for people living with dementia returning to their care home from hospital? 3) Does the care provided by hospital and care home nurses, align to best practice guidance, the components of effective transitional care, as identified by Naylor et al. (2017)?

In the previous chapter I argued that descriptive qualitative methodology was most appropriate methodology to explore these questions. In this chapter I describe stakeholder involvement, ethical approval, site and nurse recruitment procedures and characteristics of sites and participants. I then discuss data collection methods that I used (focus groups, interviews, reflexive field notes) data security and the approaches I used to analyse the data (a qualitative content analysis using an inductive and deductive approach). How the conduct of my study differed from the original plans and why is described on page 107. I complete the chapter with the techniques I used to establish rigour.

4.2. Stakeholder involvement

4.2.1. Experts by experience panel

Involving consumers of services is good practice in research, often a requirement for many research funders (Spears and Lathlean 2015) and when applying for ethical approval from the Health Research Authority. I applied to undertake this PhD study at The Doctoral Training Centre (DTC) in Transitions in Dementia Care at the University of Bradford. The original brief outline for this study was developed by the centre who involved a range of service users in the development of the outline and were praised by funders for identifying transitions in dementia care as a priority for research. The DTC formed a reference panel of people who have been directly affected by dementia. I have met regularly with them and made several presentations throughout the planning stages, during the data collection period and to share my emerging findings.

4.2.2. Health and social care professional stakeholder panel

Similarly, the DTC formed a panel of health and social care professionals working in the field of dementia care. I have presented and discussed my study with various representatives from health and social care organisations working for a mix of NHS, private, local authority and third sector providers. This has provided a richness of perspectives and these discussions have influenced my thinking when considering the design of my study, for example in discussing if I should include only nurses as participants or additionally include other professionals or family carers. Members of this group were instrumental in providing details of the people I should talk to during the planning phase of my study, for example, discharge nurses in a hospital and the coordinator of a care home research network. I was invited to clinical networks which gave me further opportunities to discuss my study with a wide range of health and social care professionals. The group also advised about recruitment and the practicalities of data collection in the clinical environment.

4.2.3. Project Advisory Group

In addition, to working with the DTC panels, I established an advisory group including two former carers of people living with dementia. One of these former carers' relative resided in a care home. I met both carers face to face, to discuss their experiences of caring. A care home manager, a care home nurse and a hospital nurse specialising in dementia care were also part of the advisory group and were available to talk through project ideas. All members of the group had copies or summaries of the project protocol, which was required for the submission for ethical approval. They read project materials such as participant information sheets, interview and focus group topic guides, participant demographic forms, consent forms and recruitment flyers, for readability (See appendix 2 for the list of participants by role and a summary of comments they made).

Although involving consumers of services is good practice, there are some challenges around representativeness. Some authors highlight that people taking part are often articulate individuals from a middle income or higher social class and as such do not fully represent a wider group interest (Spears and Lathlean, 2015). However, a service user involved in Minogue et al's (2005) study makes a useful observation, that although they recognised they were just one voice they felt they had an essential role ensuring the service user perspective was not lost throughout the study's process. I recognise that the former carers on this advisory group may not represent the views of all people with dementia and all carers but they do provide a valuable role in giving their perspective of being affected by dementia as a family carer. Furthermore, I met a family of a person with dementia who lived in a care home. Their relative had experienced two recent transitions into hospital and returned to their care home. They gave me a written account of their story which gave me an insight into some of the local challenges and some of the positive experiences they faced, from their perspective. For example, they mentioned how long it had taken on the day of discharge to wait for transport and medication, which had caused some considerable distress to the person with dementia. This increased my awareness of the challenges and influenced development of the topic guide.

4.3. Ethical Issues

I received ethical approval from the Health Research Authority for this study (Project ID IRAS number 234370). I now present the ethical issues which I identified as important for this study to address. These are, gaining consent, maintaining confidentiality and anonymity, respect for participants and the risks, benefits and challenges of taking part.

4.3.1. Consent

Informed consent from all participants was obtained, they were asked to sign a consent form (see appendix 3). This form made clear the objectives of the study, what participation would involve, the risks and benefits of taking part, facilitation of anonymity and confidentiality. The consent form was reviewed by the Project Advisory Group. As I was planning to conduct focus groups, as well as interviews, I needed to consider issues of participant withdrawal. Goodman and Evans (2015) identify that withdrawal from a focus group can be somewhat problematic, silence of an individual may mean an unease of taking part. The right to withdraw was highlighted on both consent and information sheets. I also discussed consent issues prior to the start of each focus group and reminded participants of their right to withdraw.

4.3.2. Respect for participants

Here the ethical principle of autonomy, the ability to act freely (Beauchamp and Childress, 2009) and without coercion is essential. I followed required practice and gave potential participants sufficient information and time about the study for them to decide to take part, emphasising participation was entirely voluntary (Johnson and Long 2015). This was important because potential participants were informed of the study by their managers or other work colleagues and I wanted to ensure they were under no obligation to take part.

4.3.3. Risks, benefits, and challenges

Risks and benefits were outlined in the Participant information sheet (see Appendix 4) and discussed prior to each interview or group. There was minimal risk involved in taking part. However, I noted asking nurses to reflect on care situations might reflect incidences within their clinical practice which may bring to the fore situations that were difficult or sensitive. Goodman and Evans (2015) highlight taking part in focus groups or interviews can often raise awareness about issues, which may reveal uncertainties or conflict for individuals. I identified that if support was required, referral could be made to an appropriate person or service within their organisation. No concerns were raised during the interviews or within the focus groups. Focus groups can present challenges which I needed to consider. Power imbalances within groups can exist, affecting the comfort of the participants and can inhibit participants from talking freely (Robson and McCartan, 2016). To address this, I interviewed nurse managers individually.

4.3.4. Confidentiality

Confidentiality is a requirement when conducting research and reassuring potential participants that their responses in focus groups and interviews will be confidential can increase the likelihood of them taking part (Harvey and Land 2017). Maintaining confidentiality was discussed at the beginning of each focus group and interview as a reminder to participants to keep issues discussed in the group situation confined to the group. However, as Johnson and Long (2015) highlight that during focus groups and interviews there is always the possibility that information is divulged that may present a cause for concern. For example, safeguarding concerns about individuals being put at risk of harm. To address this, at the beginning of each individual or dyadic interview or focus group I reminded participants that as nurses they must do so in accordance with the Nursing and Midwifery Council Code of Conduct (2018). If in the event concerns were aired about patient safety and public protection, then I would have to report this. No serious concerns were raised however, nurses were very open about talking about other nurses' and practitioner practices, which did uncover sub-optimal practice. Such disclosure adds value to this research in that it identifies challenges and pressures which affects roles and therefore it is imperative that confidentiality is assured. There is a fine balance in researchers judging when poor practice is identified and how a nurse researcher acts on this information to ensure public protection.

4.3.5. Anonymity

Anonymisation of participant information is good research practice and is required for the ethical review process (Robson and McCartan 2016). Identifying information described in any focus group or interview has been changed to ensure that participants are not identifiable. Nurses were informed that no personal details would appear in future publications and pseudonyms would be used. All study sites would be anonymised in all written reports and identified by letter or number. However, complete anonymity cannot be achieved within a focus group setting as participants are likely to know each other (Harvey and Land 2017), therefore participants were reminded of maintaining confidentiality as identified above.

4.4. Recruitment

4.4.1. Preparation of recruitment materials

I developed materials to recruit settings and nurses including posters, participant information sheets and participant demographic forms (see appendix 4, 5 and 6). I sent them to members of my Project Advisory Group who gave feedback which was incorporated for the final version. For example, the Project Advisory Group suggested simplifying language, such as not using the terminology of transitional care as this may not be easily understood.

4.4.2. Purposive, snowball sampling and sample size

4.4.2.1. Purposive sampling

As recommended in qualitative descriptive studies I used a purposive sampling strategy to recruit study sites and participants (Sandelowski, 2000). In purposive sampling the researcher decides who to be included in the sample based on their specialist knowledge (Hunt and Lathlean, 2015). It was important for this study to ensure nurses had knowledge and experience of care home residents’ transition back to their care home after a hospital stay, i.e. the transition under study.

4.4.2.2. Snowball sampling

I encountered difficulties in purposefully recruiting hospital nurses to take part in a focus group or interview. Despite posters, presentations at nurses' meetings and sending out information about the study, only a small number of nurses volunteered. I therefore adopted snowball sampling. Here the researcher asks initial participants to identify potential participants who might be interested in a topic. In my case, the nurses who consented to participate were instrumental in identifying other nurses who might be willing to take part. They arranged for me to see potential participants or provided my details so people could approach me. Ten hospital nurses and five care home nurses were recruited this way.

4.4.2.3. Data saturation and sample size

There is a close relationship between sample sizes and data saturation in qualitative research. As with many research proposal applications for ethical approval estimated sample sizes are required (Hammersley, 2014). In my application to the HRA, I proposed recruiting between 16-24 hospital nurses and 16-24 care home nurses. I used these sample size intentions as a guide based on studies by Hennink et al., (2017) and Guest at.al. (2017). As my original intention was to include focus group and semi-structured interviews, I considered these papers were a useful guide to inform sample size intentions in my application. Hennink et al. (2017) found that 16-24 interviews were required to reach meaning saturation, which they define as to the point where they fully understand the issues and no further insights could be found in the data. A study by Guest et al. (2017) identified saturation can be reached in three to six focus groups of six to eight people.

The concept of data saturation in qualitative methodology is the subject of much debate (Saunders et al., 2018). One of the identified issues is the range of interpretations of saturation. The original definition of saturation is derived from grounded theory research and refers to theoretical saturation where categories or themes are fully developed, the relationships or variability between them can be explained, enabling a theory to emerge (O'Reilly and Parker, 2013). In other qualitative non-grounded theory research meanings of data saturation refer to information redundancy, when enough data have been collected there is no new information being presented, indicating data collection can cease (Saunders et al., 2018). Fugard and Potts, (2015) describe how some qualitative researchers argue hard and fast rules are difficult to apply in determining sample size and that subjective researcher judgement is required in deciding the adequacy of the data in relation to the research aims and questions. There are also authors who report that who the participants are, not just how many there are in the sample will also influence data saturation, as the richness and depth of the data is an important indicator in judging adequacy in answering the research questions (Fusch and Ness, 2015), indicating quality of the interviews is important. Furthermore, they highlight that data saturation varies depending on the methodology being employed. For example, in ethnography data saturation is often more easily achieved due to multiple methods being applied over a long period of time, compared to other methodologies such as a meta-analysis which relies on the use of databases for the information and other researchers reaching data saturation. Walker (2012) who reviewed descriptions of data saturation in qualitative studies concluded that there was little consistency in its application across the studies, with the exception of grounded theory where specific guidance exists to support the use of theoretical saturation. She agrees that saturation is specific to the methodology and additionally found limited recommendations on the use of data saturation for descriptive qualitative methodologies, however her review found several examples using information redundancy as an indicator that data saturation had been reached.

I determined my final sample size using the definition of information redundancy, in that there was no new information being presented in relation to the research questions either from the interviews or focus groups. My study using qualitative descriptive methodology was not aiming to develop theory and sample size was therefore not related to theoretical saturation. However, Fawcett and Garity (2009) advise that data collected are assessed to ensure the research questions are sufficiently answered. Additionally, Elo et al., (2014) purport a judgement should be made about data saturation and that this is more easily recognised if data are analysed after the first few interviews and continues in parallel to data collection. This is the process I adopted. I reviewed interview summaries following each interview or group and from this I was able to judge if there was repetition of information and whether any new information was being presented. I confirmed this with supervisors before finalising my sample;16 hospital nurses and 17 care home nurses.

4.4.3. Recruitment of hospital and care home sites

4.4.3.1. Hospital settings

I approached two acute care NHS Hospital Trusts who agreed to take part in the study, referred to as Hospital A and Hospital B. A description of the settings is below.

One hospital (Hospital A) was recruited via a member of the stakeholder panel. As you can see below it was a large hospital and set in an urban location. The other hospital (Hospital B) I approached because it was smaller in size and in a rural location.

Table seven gives details of the two hospital sites and identifies which wards in the hospital nurses were recruited from. Both hospitals were operated by NHS Foundation Trusts and had received a ‘requires improvement’ rating for the Care Quality Commission (CQC) at the time. Attempts were made to recruit sites with variable CQC ratings to identify if there were notable differences in nursing practice. However, this aim could not be fulfilled.

Table 7: Description of hospital study sites

Hospital	Number of beds	Wards recruited from
A	800	Two short stay assessment wards 1. Acute elderly assessment ward. 2. Medical Admission Unit
		Two wards that cared for patients requiring a longer stay 1. Elderly care ward 2. Intermediate care ward
B	300	Two short stay assessment wards 1. Acute assessment unit 2. Acute Elderly medicine
		Two wards that cared for patients requiring a longer stay 1. Intermediate care ward 2. Orthopaedic ward

4.4.3.1.2. Description of wards

The short stay wards at both hospitals admitted patients either straight from community or through the emergency department. The intermediate care wards provided care for patients who were medically fit and requiring rehabilitation or ongoing care until ready for discharge. Admissions to these wards and the elderly care wards usually came from other wards within the hospital. At hospital A the intermediate care ward was not on the main hospital site and was located in the community. At Hospital B, the orthopaedic ward was for patients who had suffered a trauma and patients were mostly admitted via the emergency department. Throughout this thesis I refer to short stay wards, these include the acute assessment and medical admission wards. The intermediate care, elderly care and orthopaedic wards, I refer to as specialist wards.

4.4.3.2. Recruitment of care home settings

I was introduced to the Enabling Research in Care Homes (ENRICH) network by a stakeholder panel member. This network provides support to care homes to participate in research. I met with research nurses from ENRICH to discuss my study. In consultation with my Project Advisory Group I prepared an information sheet for care home managers (see appendix 7). On my behalf, a research nurse at ENRICH invited registered care homes to participate in the study. I was not made aware of the number approached but four expressed an interest in participating.

ENRICH informed me they contacted numerous care homes in the catchment areas of the two hospital sites that I had recruited. I was told that no care homes in the catchment of Hospital A were either interested or had capacity to participate. Only one care home in the catchment area of Hospital B was interested in taking part. The other three care home sites who were interested in participation used other district hospitals. Four care home sites CH1 to CH4 (CH= Care home) were recruited.

4.4.3.1.2. Description of care homes

A description of the care home study sites is in table eight. Each care home was privately owned. There was a mix of private providers, a business operating care homes nationally (CH1), a local family business (CH2), a business operating homes regionally (CH3) and a local business specialising in dementia care, operating two homes (CH4).

Table eight: Description of care home study sites

Care Home	Number of beds	Registered care categories	Specific nursing units	CQC rating at time of data collection
CH1	83	Care home with nursing: Old Age, Dementia and Young Adults	General nursing unit. Specialist dementia unit. Young disabled unit (Including younger people living with dementia	Good
CH2	129	Care home with nursing: Old Age, Dementia and Physical disability	General nursing unit. Unit for specialist dementia care	Requires improvement
CH3	67	Nursing care, Nursing care for people living with dementia	Not known	Requires improvement
CH4	124	Care home with nursing specialist dementia care	Smaller units offering residential and nursing care for people living with dementia	Outstanding

4.4.4. Recruitment of hospital and care home nurses

4.4.4.1. Inclusion and exclusion criteria for nurses

4.4.4.1.1. Inclusion criteria for nurses

Nurses were included if they met the following criteria:

- Registered nurses who had worked at least three months in the hospital or care home
- Discharge coordinators who were registered nurses who had experience of coordinating discharge of people with dementia back to their care home
- Hospital nurse managers who were registered nurses with responsibility or oversight of the discharge procedures
- Care home managers who were registered nurses with responsibility for transitional care procedures

4.4.4.1.2. Exclusion criteria for nurses

- Registered nurses who had worked less than three months at the hospital or care home.
- Registered nurses without sufficient English language to participate in the study.

4.4.4.2. Recruitment of hospital nurses

I worked with senior nurses and nurse managers of the two hospital sites to recruit nurses. At Hospital A, I presented my study to senior nurse managers and left copies of the participant information sheets (see appendix 4) and posters (see appendix 5) for them to disseminate. Nurses contacted me if they wanted to take part and I sent copies of the participant information sheet to them, consent forms and demographic forms. These were sent a week prior to the interview or group. These were collected and checked prior to data collection. At Hospital B, the local collaborator was helpful in advertising the study and disseminating participation information sheets. Similarly, potential participants were sent all the relevant pre-recruitment forms for completion a week prior to data collection.

4.4.4.2.1. Nurse demographics

In total 16 nurses were recruited across both hospitals. Table nine describes the demographic characteristics of hospital nurses.

Table nine: Hospital nurse demographics: gender, age and ethnicity

Participants	**Hospital A N=9**	**Hospital B N=7**	**Total in %**	**Total N=16**
Male	0	1	6%	1
Female	9	6	94%	15
Age of participants				
31-40	4	2	38%	6
41-50	3	1	25%	4
51-60	2	3	31%	5
61-70		1	6%	1
Ethnicity				
White British	7	5	75%	12
Asian other	1	2	19%	3
Black African/ Caribbean/Mixed	1		6%	1

There was just one male nurse, three-quarter of nurses were white British, and all nurses were over thirty years old. One nurse from Hospital B also worked as bank nurse at one of the care homes. Although I recruited this nurse at the care home, most of their work was conducted in the hospital. I therefore recorded their affiliation as Hospital B.

4.4.4.2.1. Years of experience and seniority of role

Table ten describes the experience and seniority of hospital nurses. A third of nurses had over twenty years of experience. Not all nurses disclosed their seniority but half of them were in a senior role

Table ten: Hospital nurses: years of experience and seniority of role

	Hospital A N=9	Hospital B N=7	Total Hospital in %	Total Hospital N=16
Years of experience as a nurse				
5-10 years	2	1	19%	3
11-20 years	4	4	50%	8
21-30 years	1	1	12%	2
31-40 years	2	1	19%	3
Seniority of role				
Matron	1		6%	1
Ward Manager	2		12%	2
Ward Sister/ Charge Nurse	2	3	32%	5
Staff Nurse	2	1	18%	3
Registered nurse seniority unknown	2	3	32%	5

4.4.4.2.2. Registration, education, and training

Table eleven gives further details of the registration, education and training of hospital nurses. All nurses were registered with the Nursing and Midwifery Council (NMC) as either an adult nurse or mental health nurse. One nurse had dual registration, meaning that they were registered as both an adult and a mental health nurse. As nurse education to enter the register has changed over time ranging from certificate, diploma and bachelor’s degree, the academic level of nurse education attainment varied. Almost half of the nurses held a bachelor’s degree.

There were three dementia champions who explained they had undertaken further training and were promoting dementia-friendly care in their area. Just over a third of nurses had received training in hospital discharge.

Table eleven: Registration, education and training of hospital nurses

	Hospital A N=9	Hospital B N=7	Totals N=16	%
Nurse registration	9 Adult	6 Adult,1 Dual	15 Adult, 1 Dual	94% Adult 6% Dual
Academic level	2 Certificate 3 Diploma 4 BSc	1 Certificate 3 Diploma 3 BSc	3 Certificate, 6 Diploma 7 BSc	18% Certificate, 38% Diploma 44% BSc
Dementia training	9 (3 Dementia champions)	7	16	100% trained
Hospital discharge training	3	3	6	38% trained

4.4.4.3. Recruitment of care home nurses

The ENRICH network gave me contact details of the four care home managers who had expressed interest in participation. I met with them to discuss the study and agreed to either conduct focus groups or individual interviews. I sent participant information sheets (see appendix 4) to the care home managers for dissemination to any potential interested participants. Potential participants expressing an interest were sent consent forms and participant demographic forms (appendix 3 and 4) for completion at least one week prior to interviews or group.

4.4.4.3.1. Nurse demographics

In total 17 care home nurses were recruited across the four care home sites. Table twelve describes the demographic characteristics of care home nurses.

Only one nurse from CH3 was recruited and interviewed. On the day arranged to recruit and interview nurses from CH3, only two nurses were released due to unforeseen medical events occurring in the home. One of these nurses did not meet the inclusion criteria as they had not worked in the care home for over three months. Further visits to CH3 were difficult to arrange, and I was then informed by ENRICH that the home was closing.

Table twelve: Care home nurse demographics: gender, age and ethnicity

Participants	**CH1 N=8**	**CH2 N=4**	**CH3 N=1**	**CH4 N=4**	**Total in %**	**Totals N=17**
Male	3	0	0	2	30%	5
Female	5	4	1	2	70%	12
Age of participants						
18-30	0	0	1	1	12%	2
31-40	5	0		2	42%	7
41-50	2	1		1	23%	4
51-60	1	3			23%	4
Ethnicity						
White British	2	3		3	48%	8
European	2				12%	2
Asian British		1			5%	1
Asian other	4		1		30%	5
Black African/ Caribbean/Mixed				1	5%	1

More males were represented to that of the hospital nurse sample. There was also more diversity in the care home sample with an almost fifty-fifty split between white British and other ethnicities. There was a similar age profile to that of the hospital nurses although two nurses were under thirty years old.

4.4.4.3.2. Years of experience and seniority of role

Table thirteen describes the experience and seniority of care home nurses. Similarly, to hospital nurses just under a third had over twenty years of experience. There were fewer care home nurses in senior roles, compared to hospital nurses.

Table thirteen: Care home nurses: years of experience and seniority of role

	CH1 N=8	CH2 N=4	CH3 N=1	CH4 N=4	Total CH in %	Totals N=17
Years of experience						
≤ 5 years			1		5%	1
5-10 years	4			3	41%	7
11-20 years	2			1	18%	3
21-30 years	1	2			18%	3
31-40 years	1	2			18%	3
Seniority of role						
Deputy Matron		1			5%	1
Clinical Lead				1	5%	1
Team Leader/Unit Manager	3	1			25%	4
Registered Nurses seniority unknown	5	2	1	3	65%	11

4.4.4.3.3. Registration, education, and training

Table fourteen gives details of the registration, education and training of care home nurses. There were more mental health nurses to that of hospital nurses. The academic attainment was higher to that of the hospital nurses with four care home nurses holding master's degrees. Just two nurses had received training in hospital discharge as they had previously worked in an intermediate care service.

Table fourteen: **Registration, education, and training of care home nurses**

	CH1 N=8	CH2 N=4	CH3 N=1	CH4 N=4	Totals N=17	Total CH nurses in %
Nurse registration	6 Adult 2 Mental health	3 Adult 1 Dual	1 Adult	1 Adult 3 Mental health	11 Adult 5 MH 1 Dual	65% Adult 30% MH 5% Dual
Academic level	3 Diploma 1 BSc 4 MSc	1 Certificate 1 Diploma 2 BSc	1 BSc	2 Diploma 2 BSc	1 Cert. 6 Dip 6 BSc 4 MSc	5% Cert 35% Dip 35% BSc 25% MSc
Dementia training	8	4	1	3	16	95%
Hospital discharge training	2	0	0	0	2	12%

4.5. Data collection

In this section I detail the data collection methods used and explain the rationale for using them. I discuss how I conducted the field work, I present my professional background, discussing how this may have influenced data collection. I share some of my reflections during the data collection period and discuss the safe storage of the data I collected.

4.5.1. Focus groups

Focus groups are an effective way of developing insights about situations that may not be otherwise discussed (Rabionet, 2011; George, 2013). As a nurse myself, I considered it would be rare for nurses to get the opportunity to sit together and reflect on transitional care practice and thought a focus group format would create such an opportunity. Kitzinger (1994) purports that focus groups provide opportunity for rich discussion as participants can query each other to discover deeper meanings and the interactions between participants can also provide further insights. Focus groups vary in size, but typically include between five and twelve participants (Goodman and Evans, 2015).

It was therefore my original intention to collect data primarily through the use of focus groups. However, I also envisaged I would need to collect data via individual interviews, in particular with nurse managers, as I considered having them present in a group may inhibit group discussion. I also expected that some nurses might want to take part but may be unable to attend at a specific time of such a group because of their work commitments. I considered offering interviews in addition to focus groups to potential participants would be a satisfactory way of obtaining their insights.

I appreciated these two methods may yield different types of findings as the data derived from focus groups also includes the interaction between group members and how participants respond to each other, which would be missing from individual interviews. However, Baillie, (2019) observed that interviews are often complementary to focus groups within qualitative studies and can be commonly replaced if focus groups are difficult to arrange. Baillie (2019) recommends that in such cases the source of data is considered in the analysis. For clarity, I indicate throughout my findings whether the data came from an interview or focus group.

Only care home nurses participated in focus groups. In common with other researchers who have cited difficulties in health professionals attending focus group studies (Baillie, 2019), it proved very difficult for hospital nurses to be released from their role to attend a group. Two focus groups were held and seven care home nurses participated: three from CH1 and four from CH4. Although two focus groups were arranged at Hospital A, poor attendance meant these could not take place. Although the focus groups held in my study were not the optimum size, Gill et al. (2008) noted focus groups can work with as few as three people. There were two group facilitators, myself and one of my supervisors.

4.5.2. Semi-structured interviews

There are three types of interviews along a continuum of unstructured, semi-structured to structured (Tod, 2015). I chose to use semi structured interviews as I considered some structure to steer the interview would be necessary. I deemed time might be an issue for nurses, who were being released during their working shifts. The flexibility of semi structured interviews does allow for some diversion from the topic guide for relevant issues to be discussed that may not have been anticipated by the researcher (Harvey and Land, 2017). Bradshaw et al. (2017) suggest semi structured interviews are useful for ‘encouraging depth’ contributing to the ‘richness of data’ which is required in qualitative descriptive designs. Interviews can be conducted face-face, one-to-one (individual) or dyadic (two participants). I describe use of each in my study below.

Early in the data collection process it became clear semi-structured interviews were the most practical method and they became the predominant data collection method. Although this was not my original intention, I considered flexibility was required to fit in with the participants and to meet the challenges of conducting research in busy hospital and care home environments. Previous studies have identified that nurses in hospitals rarely have protected time for participating in research activities (Loke et al, 2014) and researchers have identified numerous challenges in undertaking research in care homes requiring a flexible and pragmatic approach to overcome these challenges (Jenkins et al., 2016).

4.5.2. Individual interviews

Fourteen of the sixteen hospital nurses and eight of the seventeen care home nurses took part in individual interviews. Most of these interviews were conducted in a quiet room located on the ward or in the care home. Ideally interviews were to last an hour, however this proved challenging with the busy care environment and several nurses were unable to commit to a full hour. One nurse was called back into the care environment due to a medical emergency before the interview could be completed. Four hospital nurse and four care home nurse interviews were interrupted. All data were used even if interviews were terminated prematurely.

4.5.2.2. Dyadic interviews

Four nurses took part in dyadic interviews. Dyadic interviews involve interviewing two individuals who are not in a close relationship to each other, i.e. family members. It is not a well-researched method of data collection but there is some evidence to support its merit. Morgan et al. (2013) suggests it offers similar advantages to focus groups on the sharing and comparing of issues discussed and that the process of interaction between the two individuals can also be of interest. They support their use when focus groups are problematic to organise. I used a change of approach when focus groups were poorly attended and used dyadic interviews in two settings, one at CH1 and one at Hospital A. I acknowledge that this will lead to yet another variability in the data which I have acknowledged in the analysis.

4.5.3. Topic guide

The topic guide for the interviews and focus groups (see appendix 8) was created using findings in the literature, as is best practice (McLafferty, 2004). Best practice indicates topic guides include a set of questions and probes to encourage depth of exploration (Harvey and Land, 2017). Early versions of the topic guide used language from Naylor’s best practice framework of transitional care (Naylor et al.’s, 2017) (see appendix 9 for draft 1 of topic guide). However, nurses on the Project Advisory Group felt some of the language may not resonate with UK nurses. The care home nurse on the group had tested out the topic guide with a colleague. They advised me to simplify the questions, not to use the terms such as ‘components of care’ and ‘transitional care’ as this was not everyday language for UK nurses. I therefore developed the topic guide to ask more broadly what their experience was of preparing a person for their transfer of care and asked further probing questions about how they managed a person’s complex needs at this time (See appendix 10 for draft 2).

In early interviews issues arose which I had not come across in the literature. For example, nurses raised the issue of lengthy journeys between settings and the impact this could have on people living with dementia. I developed questions around this. As such, the topic guide evolved over time (See appendix 8-10 for versions).

4.5.4. Reflexive field notes

During data collection I made interview summaries after each episode of data collection and kept reflective field notes. Kent (2015) describes reflexivity as the process of researcher reflection of their own values, perceptions and actions which may impact on the setting, data collection and analysis. Maintaining reflective notes throughout the data collection and analysis process can therefore demonstrate how the researcher has influenced the research.

4.5.4.1. Professional background and Insider position

I am a mental health nurse with a special interest in dementia care and have worked in both a hospital and community settings. These experiences grounding my knowledge and understanding of the wide range of issues that people with dementia and their families face during their journey. I appreciate that collaborative working with a range of professionals is an essential component for providing quality care to people with dementia and their families. I have witnessed challenges of working across health and social care systems and realised barriers often exist which result in sub-optimal care for people living with dementia.

It is important that I acknowledge my background and consider its impact of this on my study. The degree to which a researcher is located either within or outside a group being researched referred to as insider/outsider stance (Gair, 2012). There can be both advantages and disadvantages of having a common lived experience to that of the group being researched. Berger (2013) suggests that potential advantages are an ease of access to the field and participants being willing to share experiences with someone who may have empathy for their situation. It may influence the researcher and participant relationship which may impact on the information shared, they may feel more comfortable sharing knowledge (Berger, 2015). In my case I believe it helped me gain access to the field and build a rapport with nurses.

On the other hand Lathlean (2015) highlights that being a member of the same professional group may activate biases and beliefs about roles and settings, which will need to be exposed, as this can influence meaning and interpretations that are made by the researcher. Braun and Clarke (2013) argue the essence of qualitative methods is that they recognise the researcher as the instrument in the research and that although codes and categories and themes are grounded in the data collected, they are inevitably developed from the researcher’s standpoint.

Given I am a nurse studying nurses’ roles it was important for me to be aware of these issues and keep a record of how my role has influenced data collection and the findings. I now discuss this in my reflections of how I recruited nurses and collected data.

4.5.4.2. Reflexivity of data collection

I used my professional background to recruit and build relationships with the nurses and managers working in the hospital and care home settings. I explained from the outset I was a nurse; with the hope this may put them at ease. I used my knowledge of the clinical environment to work with nurse managers to identify the best time to undertake data collection.

Although this may have some advantages, in that I was able to demonstrate insights and develop empathy, it is possible my insider position influenced how I conducted the interviews. I was very aware that nurses were taking time out of their clinical day and many had time pressures. My notes reflect that I often felt rushed during the interviews, the nurses appeared rushed and it led me to question had I influenced the rushed feeling. Perhaps a non-clinical person may not have felt this pressure. To counteract this, I made conscious efforts to provide a relaxing environment, by providing refreshments. I became more relaxed about interruptions and tried foster a sense of calm. I also wanted to ensure they did not think they were being judged or tested.

It was useful to have supervisors to co-facilitate focus groups, and a co-facilitator was also present for one individual interview and one dyadic interview. Although I was the main interviewer, as a novice researcher it was helpful to reflect on the interviews afterwards and gain feedback on my interviewing techniques and consider areas of strengths and areas for improvement. For example, summarising what people had said and checking out meaning.

I decided to carry out data collection at both hospital and care home sites during the same time-period. I considered it might be helpful to hear both hospital and care home nurses' perspectives early in the study to gain insight into both ends of the transition. I used information gleaned from one setting to understand more about a specific process in another setting. For example, I learned that several care home nurses had trouble accessing information about their resident when they were admitted to hospital, and I wanted to find out from the hospital perspective the process for sharing information. This enabled me to gain a more complete picture of the processes from the perspectives of nurses between hospital and care home settings.

4.5.5. Data storage and protection

Study data were handled in compliance with the Data Protection Act (1998) and the General Data Protection Regulations (2018). Focus groups and interviews were recorded on an encrypted, password-protected digital recorder. They were transcribed, anonymised and stored on a password protected university computer (McFarlane and Bucknall 2015). Recordings were downloaded and transcribed promptly and deleted from the recording device immediately after transcription. All NVivo databases created were password-protected. All information will be retained for five years as per university policy.

4.6. Data Analysis

In this section I provide a detailed overview of the qualitative content analysis I conducted. I used an inductive qualitative content analysis to answer my first two research questions about nurses' roles and what facilitates optimal care. I then used a qualitative deductive analysis to assess the extent to which nurses' perspectives on their roles align on to Naylor, et al.'s, (2017) best practice care component model.

4.6.1. Qualitative content analysis

Qualitative content analysis involves a systematic and categorising approach for exploring trends and patterns in the data (Hsieh and Shannon, 2005).

Qualitative content analysis keeps the researcher close to the data and enables a description of the phenomena being studied and is the recommended strategy of analysis in qualitative descriptive methodology (Sandelowski, 2000). Hsieh and Shannon (2005) explain three types of qualitative content analysis: conventional, directed, and summative. A conventional approach is inductive, codes are generated directly from the text with no preconceived framework. A directed approach is deductive, the analysis starts with research findings or theoretical framework and data is searched to find those pre-determined codes. A summative content analysis entails counting and comparing key words or content within the text. I used both inductive and deductive approaches.

There has been some debate about the terms ‘inductive’ and ‘deductive.’ Armat et al. (2018) point out using an inductive approach the researcher uses their previous knowledge from literature, their research aims and questions and therefore there is an element of deduction. They point out that during a deductive approach, inevitably new concepts may be generated inductively. They conclude that one approach may be more dominant than the other and suggest terms such as ‘inductive dominant’ and ‘deductive dominant’. This is the terminology that I will use.

There are three main steps in conducting a qualitative content analysis 1) preparation phase, 2) an organising phase and 3) reporting the analysing process and results through models, concepts, categories (Elo and Kyngäs, 2008). In content analysis researchers can decide to report either manifest content, the descriptive level of the content, or latent content as well which is looking for underlying meanings, often interpreted from silences and expression for example, sighs, laughter (Elo and Kyngäs, 2008). I now describe how I applied the three stages of qualitative content analysis when analysing my data.

4.6.1.1. Preparation phase

The preparation phase includes deciding on the sampling strategy the data collection methods (Elo et al., 2014) which have been highlighted in sections 4.4 and 4.5.

The next stage is selecting the unit of analysis and being immersed in the data. Graneheim and Lundman (2004) suggest whole interviews as units of analysis. I selected either the whole interview or the focus group. I immersed myself in the data by listening to recordings and writing summaries and reflections immediately after each interview and focus group. I transcribed the first focus group, dyadic interview and three individual interviews. The remaining 21 transcripts were transcribed by a professional transcribing service. I listened to each recording several times comparing the transcript and checking for accuracy. Any inaccuracies in the transcripts were corrected. Listening to the recording, transcribing or checking enables familiarisation with the data. Braun and Clarke (2013) highlight checking transcripts against recordings ensures they remain ‘true’ to the original source, such as ensuring punctuation are applied for correct meaning. Reading through the transcripts enabled me to see some of the pertinent and repeated patterns. I found listening to the recordings an invaluable process, hearing the voices, the nuances of tone also identified more latent content, for example hearing sighs and expressions of frustration when information was not received.

In addition to interview transcripts, I also used demographic data and my reflexive field notes throughout the analysis process. My reflexive field notes consisted of the summary of each interview and group and incorporated any reflections/notes made during the interview or group. I read through my reflexive field notes to inform and compare my interpretations. I cross referenced data from individuals to their corresponding demographic details which gave me information about their role, place of work, years of experience, training and education. Referring to these extra sources of data supported my understanding of the meaning I was able to interpret from the data, make judgments and identify and interpret any patterns.

The aim of immersing oneself in the data in this way is obtaining a sense of the whole and deciding analysis of manifest or latent content (Vaismoradi et al., 2013) To answer my first research question, I decided I would need to report manifest content, a description of the nurses’ roles. I had also identified latent content and I considered this would be helpful in identifying the facilitators for providing care. I decided that I would report on both.

To manage the data, I used a computer assisted qualitative data analysis package. Transcripts were anonymised and loaded into a NVivo database (version11). Robson and McCartan (2016) state advantages of using computer software include the ability to manage large quantities of data and help to facilitate in the development of consistent coding.

4.6.1.2. Organising phase

The organising phase involves coding, creating subcategories, categories and themes across the data set (Elo and Kyngäs, 2008). I used an inductive-dominant approach to derive codes from the data. Codes are labels which the researcher assigns to the data which they consider to be of interest (Hsieh and Shannon, 2005).

4.6.1.2.1. Coding

I engaged in coding some of the early transcripts prior to completion of all interviews. Other researchers were also involved, my supervisors and a colleague from the faculty. Each researcher was aware of the aims of the study and had copies of the research questions. I coded four of the twenty-six transcripts (15%) and each of the four transcripts were coded by two other colleagues. Each researcher read each transcript line by line, identifying headings, writing notes to describe aspects of the data (Elo and Kyngäs, 2008). Researchers met together to compare transcripts and headings. An initial set of forty-two codes were agreed. These were entered into the NVivo database. I independently coded the remaining transcripts using these initial codes and if new topics and concepts arose, I derived new codes.

Further examination of the codes revealed a mix of both manifest and latent codes, although more latent codes had been identified. During the immersive stage I had considered there were more specific actions and activities that nurses performed which were not identifiable in the codes. I therefore re-read all transcripts again and line by line identified manifest content of nursing actions and tasks and derived a further set of codes. A second researcher checked the most populated codes. This checking process involved the discussion of issues about content which had been coded and verifying that the content matched the code. Latent content codes for example ‘hospital nurse empathy’, ‘frustrated with care home’ were checked to make sure any of the nuances such as tone and silences were not over interpreted as Elo and Kyngäs (2008) recommend. The final set of codes were discussed and agreed with my supervisory team.

4.6.1.2.2. Creating subcategories, categories and themes

Categories and sub-categories are developed by grouping together codes which appear to be linked or related to each other (Hsieh and Shannon, 2005). Vaismoradi et al. (2016) purports a category refers to manifest content and a theme is more implicit referring to latent content. Therefore, themes express underlying meanings which are found across categories (Erlingsson and Brysiewicz, 2017). Theme development is known to be the most abstract result following extensive engagement in the analysis process (Vaismoradi and Snelgrove, 2019).

I examined all the codes and I could detect a pattern that the nursing actions and tasks that nurses described were taking place across four phases of a transition pathway. Similarly, a transition pathway had been identified in a previous study on hospital discharge (Waring et al., 2014). I initially grouped codes into four categories representing the four phases:

1. When the resident is admitted to hospital
2. During the resident’s stay in hospital
3. On the day the resident is discharged from hospital
4. After the resident returns to the care home

On further examination of the data, I detected further patterns, I rearranged the codes. I found specific nursing tasks that made up a nursing activity. For example, codes such as ‘complete nurse to nurse handover forms,’ ‘fill out red bag paperwork’ ‘give a verbal handover’ were grouped together and I formed a sub-category which I named ‘providing information’. The subcategories I created refer to nursing activities. I then grouped the subcategories into a smaller number of categories. For example, ‘providing information' became a subcategory of the category 'exchanging information'. I created four categories which were nursing roles. One form of qualitative data analysis involves counting the number of instances topics are raised or counting the numbers of individuals or groups which contribute to meaning saturation of a category or theme (Hennink, et.al., 2019). I did not employ a quantitative approach to establish meaning saturation. Instead, I followed Braun and Clarke's (2021) view that frequency alone does not determine the significance of what is meaningful but that each theme (or category) contributes relevance and usefulness to the story which in turn answers the research question.

Some researchers view that data saturation can be more easily applied to surface (manifest) content (Braun and Clarke 2020), for example, when developing categories. I judged that there were adequate data to develop the four main categories. All participants at least to some degree described nursing activities which made up these categories. When I report the findings in chapter five, six and seven I have given details of participants contributing to the sub-categories and to what extent I consider the subcategories reach saturation.

Examples of codes, subcategories and categories can be found in appendix eleven.

As I engaged with the analysis more deeply over time, and cross-referenced demographic data and my reflexive field notes, I saw contextual patterns in the data which added further meanings. For example, there was a pattern in that nurses performed their roles differently which was dependent on the location of the ward or the care home. I could see that this role variation occurred in all four of the categories. I generated four themes relating to the categories; Interdependent roles; variation in roles; distinct needs of people living with dementia and care home exclusion. As I interpreted these patterns across the four categories I made a judgement about the relevance of these themes to the overall story about the nurses' role in transitional care, answering my first research question. At this point, I had already presented my data at several conferences, clinical networks and stakeholder groups.

Discussions at these events also added weight to the findings from my study and helped with interpreting them. For example, at a clinical network event, care home and hospital-based nurses who had not participated in the study discussed their interdependent roles, agreeing with each other there was significant independence on each other to execute their own role. This was a theme I had generated from my data when examining the data across the categories. The feedback from the conference presentations also contributed to the saturation of these themes.

The visual representation of the categories and themes can be found in figure three.

Next, I sought to answer the second research question and identify the facilitators for providing optimal care. I examined codes and looked for facilitators. Many latent content codes made up the facilitators. For example, codes such ‘care home nurse empathy’ and ‘judgement of positive practice’. Again, I referred to all data sources to support interpretations. For example, I generated the theme building positive relationships. Although only a few nurses mentioned this as a definitive facilitator, other nurses who discussed the adverse consequences of poor nurse relationships between the settings resulting in poor care outcomes. I had noted this in my reflections there were barriers that the opposite would infer better care. I used this reflection to support the meaning of this theme. As I grouped these codes, I found patterns relating to facilitators which were identified across the four categories. I found four themes which facilitated the nurses’ roles in providing optimal care. An example of the codes and themes can be found in appendix twelve. A visual representation is in figure four.

My professional background and knowledge of nursing roles may have influenced the decisions and interpretations I made in creating categories, subcategories, and themes. I had regular discussions with supervisors throughout the process as a means of checking out my interpretations.

4.6.1.3. Reporting the analysing process and results through models, concepts, and categories

The final stage in the qualitative content analysis process is the tool that is used to present the findings, this can be through the themes or categories that have been developed (Vaismoradi et al., 2013). In deductive-dominant approaches findings are presented through existing or adapted models or conceptual frameworks (Elo and Kyngäs 2008). To answer my first research questions findings will be reported through four categories of role, and four themes relating to the nurses' role. The second research question will be reported through four themed facilitators. See figures three and four.

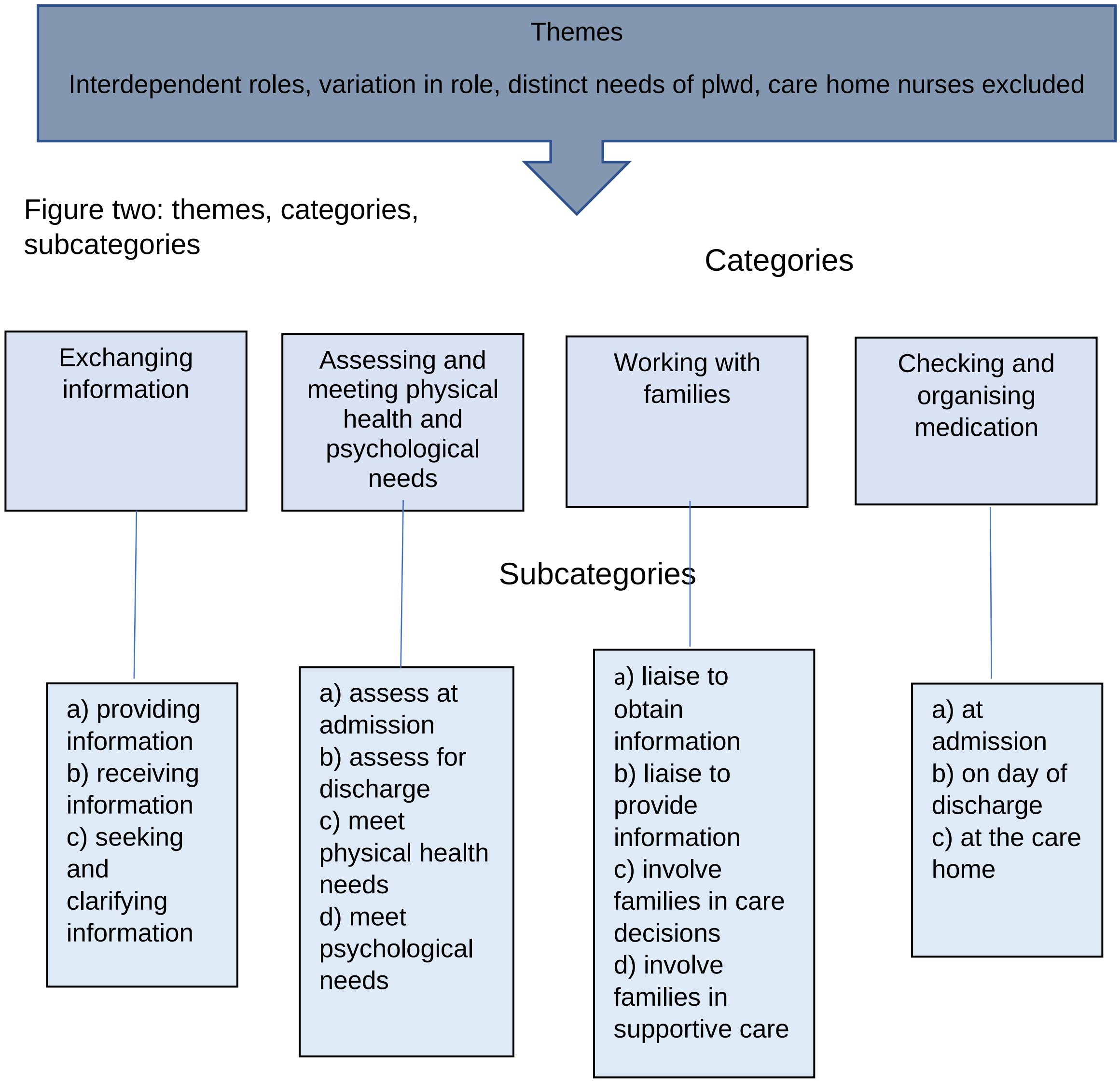
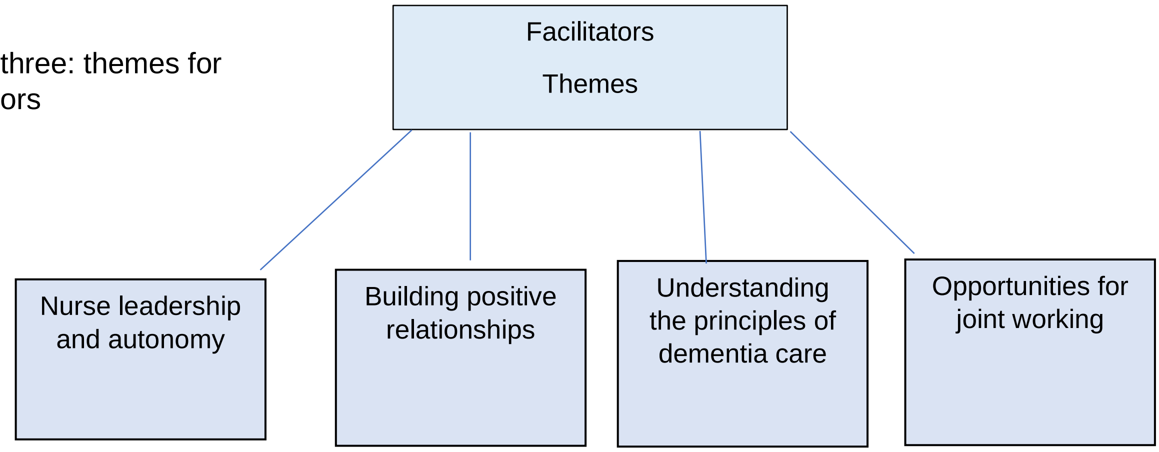


Figure two: themes, categories, subcategories

Figure three: themes for facilitators



I now present some of my reflexive notes of the inductive-dominant qualitative content analytical process.

4.6.1.4. Reflexive field notes

4.6.1.4.1. Reflexive considerations during familiarisation processes

Listening to the recordings of interviews and focus groups I was struck by how much frustration was expressed when nurses talked about each other's practice. For example, in the context of information exchange, where there was a hand-off of information. Although not everyone stated they were frustrated or angry I could tell from the pitch and tones in their voices. I considered it important to capture this and I wrote notes when this was happening. I noted there were other nurses who were very calm when they talked about shortcomings in other nurses' practice. They had a more patient tone and would put forward an alternative reason why something may have or not have happened. For example, a care home nurse acknowledged hospital nurses were under pressure. Hospital and care home nurses expressed frustration about systems of working, for example incompatible electronic systems to exchange information. I was aware I had experienced similar frustrations when I worked in clinical practice. I believed it was often a disharmonious process. I was cognisant to minimise the bias I may be bringing to the analysis by actively seeking the deviant case, in this context points of good practice.

4.6.1.4.2. Reflexive considerations during coding

I found there were many issues and perspectives, not just expressed by nurses in the study but also my own as a clinician. I therefore found it useful for other researchers to help with coding my data, and review codes together. Where there were similarities in the codes we identified, it gave me reassurance that the data could be interpreted in this way. However, there were instances where data had been coded by me and not my researcher colleagues and vice versa. This led me to take a closer look at these data to see if I had missed anything. I found myself justifying why I had coded the data in the way I had and this made me realise this could be a process of influencing other coders as discussed by authors Braun and Clarke (2013). One researcher who was also a nurse questioned some of my codes which prompted me to listen to the recordings again to double-check coding. This was often in relation to conflict and judgement, where tone of voice used also had a bearing on coding of content. Developing categories and themes was an iterative process and the more I looked through the codes and the demographics I found various patterns. Taking breaks away from the data was helpful, going back to the data helped me to gain new insights.

4.6.2. Deductive qualitative content analysis

In this section I describe how I used a deductive-dominant content analysis approach to assess the extent to which nurses' perspectives on their roles align on to Naylor et al.'s, (2017) components of transitional care model. First, I give an overview of directed content analysis (deductive-dominant). I provide a justification for using Naylor et al.'s, (2017) model. I then describe how I used it to answer the question.

The deductive-dominant approach has similar preparation phases to an inductive-dominant approach. As the purpose of using a deductive-dominant approach is to retest an existing model in new context, it involves developing a categorisation matrix from the model you want to test (Elo and Kyngäs, 2008). All the data are reviewed for content and coded for correspondence with the identified categories (Elo and Kyngäs 2008). If data are found that does not fit with the pre-determined coding schemes, new codes can be created (Hsieh and Shannon, 2005). A limitation of the deductive-dominant approach is the researcher is approaching the data with a strong bias which may influence the researcher to find evidence to support the theory or model (Hsieh and Shannon, 2005).

4.6.2.1. Justification for using Components of effective transitional care (Naylor et al., 2017)

In chapter one, I described best practice models of transitional care which were developed to support the implementation of effective care delivery when a patient is discharged from hospital back to their own home. Two models were developed in the US by Burke et al. (2013) and Naylor et.al. (2017). Although the US healthcare system is different to that in the UK, these US models of care provided more detail about individual care strategies in meeting effective transitional care to that of UK NICE guidance (2015). The NICE (2015) guidance sets out a broad set of principles for guiding care when a person transitions from hospital into the community setting. Although clinical guidelines are often drawn from scientific evidence and expert consensus, debate exists about their limitations (Perleth et al., 2001). Some argue they can lack scientific evidence, that expert opinion can be biased and that some members of the group may also have financial interests (Greenfield, 2017).

I therefore chose to use one of the US models and I selected the model developed by Naylor et al. (2017). This was the most recent model which was developed from scientific evidence and the research team had involved a range of stakeholders including patients and carers in developing the model. The authors also applied the model of care to a case example of an older person with complex health care needs which included cognitive impairment. I considered this was the closest model of care to use for my study, as the transition I was studying was people living with dementia. However, Naylor et al.'s, (2017) components of care were developed for hospital to home transitions so I was cognisant this may not be an exact fit.

4.6.2.2. Conducting the deductive-dominant analysis

The Naylor et al., (2017) model consists of eight care components:

- Complexity Management

- Care continuity
- Patient and (family) caregiver well-being
- Accountability
- Family carer engagement
- Patient engagement
- Patient education
- Caregiver education

The components of care should be addressed by health care systems during transitional care to deliver best practice (Naylor et al., 2017). To achieve meeting each component of care a set of suggested operational strategies were developed. The suggested strategies were not developed specifically for nurses, Naylor et al., (2017) refer to clinicians. Despite this, I considered that many of the strategies suggested could be applied to activities undertaken by nurses.

I used the suggested strategies within each care component as the predetermined categories to align my data to. However, I made some modifications to the deductive-dominant approach. Qualitative content analysis does allow for some flexibility and Elo and Kyngäs (2008: 113) say there is “no simple, ‘right’ way of doing it”. I did not code the data again, but I examined the data in the subcategories developed from the inductive-dominant analysis and aligned the subcategories (nursing activities) against each of Naylor et al.’s,(2017) suggested strategies for each care component. If no nursing activities were aligned, I identified the gaps. I found data which was not acknowledged in the Naylor et al. (2017) model of care because it was developed for hospital to home transitions. I therefore created new strategies which reflected the hospital to care home transition.

The tool I use to present this analysis is provided in chapter seven where I report on the findings and indicate the degree of alignment of nurse activities to the suggested strategies in the Naylor, et al., (2017) model. In regard to the concept of data saturation this would be the degree to which the data were saturated into each category and sub-category. I acknowledge in the summary instances where data saturation was not reached. The lack of saturation here shows the degree of applicability or otherwise of the model, the adaptations required and where further research is needed for its use in the UK. I now present my reflexive field notes of the deductive-dominant analytical process.

4.6.2.3. Reflexive field notes using a deductive-dominant analytical approach

I used my nursing knowledge to interpret nursing activity alignment to the strategies suggested for meeting each care component. I identified specific components of care that I may have not explicitly asked about during the interviews, for example, patient and family carer education. I considered this could have potential limitations perhaps if I had probed about these care components during interview they may have been disclosed. Alternatively, their lack of discussion may suggest they are not prominent roles within the transition. Furthermore, I was aware of the bias limitations of using the deductive approach. It was therefore important to have regular discussions with my supervisors about the decisions I made aligning nursing activities to the model of care.

4.7. Rigour

To establish rigour in this qualitative process of data collection and analysis, I employed several techniques as recognised good practice (Tuckett, 2005: Colorafi and Evans, 2016; Bradshaw et al., 2017). In this section I outline how I conducted transcript review, interpretive rigour, confirmability and transferability.

4.7.1. Transcript review

Transcript review involves returning the transcript of the interview to the participant to check validity to ensure it is a true account of what was discussed (Polit and Beck, 2014). It is one of the steps in ‘member checking’ which also includes involving participants in validating interpretations. It is viewed by many as adding credibility to the findings (Tuckett, 2005). Authors have added that transcript review is polite and compensatory for the time the participants have given to the study (Mero-Jaffe, 2011). However, others have suggested it can be burdensome to the interviewee (Hagens et al., 2009).

I offered the nurses copies of their transcripts to give them the opportunity to check the content for any misrepresentations. Nine out of the thirty-three nurses requested copies. Five of the nurses were given the transcripts in person and I was available to discuss the transcript if required. The other four were sent transcripts with details about how to contact me about any corrections. No corrections or amendments were requested. The relatively low take up of this offer may be due to the burdensome nature of the task, in many cases transcripts were lengthy documents, in that many were over thirty pages long.

4.7.2. Interpretive rigour

Morse (2015) argues that interpretive rigour is enhanced by involving more than one person in the coding. This is known as inter-rater reliability. It is somewhat controversial in that Braun and Clarke (2013) do not advocate second person coding, purporting that there is no accurate way to code and that multiple researchers are often influenced by each other when coding the data. Validation of codes is common in qualitative content analysis (Vaismoradi et al., 2013). I therefore took measures to involve other researchers in validating codes.

4.7.3. Confirmability

Good qualitative research reports findings that are grounded in participants words and actions (Korstjens and Moser, 2017). Keeping records of your research process and being transparent about how you have derived conclusions is important. I have given an honest account of how I made decisions within my analysis. I also kept reflexive field notes. Although I offered nurses the opportunity to read the transcripts, I did not undertake a further step of member checking, (presenting initial findings to the participants to see if they reflect accuracy) due to time constraints and practical issues involved in getting nurses together. Furthermore, Morse (2015) argues this is not a necessary step and highlights various problems. She states participants may find it difficult to find their own story in presented findings as they are often a synthesis of all interview data. She also highlights dilemmas for the researcher about how to proceed if there is a disagreement with researcher interpretation. She advocates member checks during data collection processes such as clarifying understanding during interviews as good practice. Checking out what other participants have shared to see if they have similar experiences or views is also recommended. I used both techniques in many of my interviews which can be identified in the transcripts.

Other authors recommend discussing findings with other practitioners to find out if findings are plausible, as means of contributing to confirmability (Colorafi and Evans, 2016). I have presented findings at one international and two national conferences attended by researchers and nurses (see appendix thirteen for a list of paper titles and conferences where I presented). I also presented at a regional clinical network where several professionals from both primary and acute care were present as well as people directly affected by dementia. These were good opportunities to check out my findings with those working in the field and those who have experienced transitional care. I was encouraged that findings in this study resonated with practitioners and people affected by dementia from different geographical locations.

Deviant case examples are considered an important way of countering researcher bias (Robson and McCarten, 2016). This is taking note of the uncommon cases and comparing it to the frequently occurring ones and trying to understand differences to gain a more thorough understanding of the situation. This process also supports validity (Morse, 2015). I made efforts to do this, for example, noting when nurses deviated from usual procedures.

Triangulation is a research strategy which uses multiple sources to enhance credibility as it aims to provide a complete analysis (Nowell et al., 2017). I have aimed to do this in two ways. By investigating both hospital and care home nurse perspectives of transitional care I hope to gain a complete understanding of the transition from both sides of the pathway. By using a best practice model to assess the extent to which nursing roles match best practice, I have used a form of theoretical triangulation, to understand if nurses are optimising care at this transition. Theoretical triangulation can support the researcher to support or refute findings (Carter et al., 2014).

4.7.4 Transferability

Transferability is the term in qualitative studies that describes the extent to which research findings can be applied to other similar populations in other similar settings (Colarfi and Evans, 2017). It is distinct from generalisability, which is the aim in quantitative research for the results to apply to the study's whole population (Harvey and Land, 2017). A common interpretation of transferability is that the reader takes responsibility for judging whether the findings are applicable to their own context (Tuckett, 2005, Connelly, 2016), but this relies on the researcher fully describing the characteristics of the sample, the setting and the processes undertaken in the study (Miles et al., 2014).

In section 4.4.3, I therefore provide this information by describing the hospital and care home settings I recruited into the study. I provide details of the number of beds at each hospital, the nature of their location (rural and urban) and the CQC quality rating. I have also described the type of ward from which the nurses were recruited. Similarly, I have supplied full data on the care home settings, which included size, CQC quality rating, the categories of care they provided and their type of ownership.

In section 4.4.4, I provide characteristics of both the hospital and care home nurses who participated in the study. This includes their gender, age, self ascribed ethnicity, years of experience, role seniority and details of their registration, education and training. Although the age of these nurses appears to be high, it does compare to the age profile of nursing registrants in 2018 (RCN, 2018). Forero et al., (2018) argues that researchers should ensure that the participants are selected are both representative and knowledgeable about the phenomena being studied. My inclusion criteria were that participants had at least three months of experience in the setting, however the majority of participants had considerably longer, with many having extensive nursing experience. The participants therefore met the inclusion criteria and were working in settings that ensured that they would have experience of working with people transitioning between acute settings and care homes. Their experiences and views would be of relevance to other such settings.

According to Miles et al., (2014) another facet of transferability is for a range of readers to report that the findings are consistent with their own experience. This is also a method contributing to confirmability as highlighted in section 4.7.3. Through the various presentations I have conducted I have demonstrated I purposively sought out resonance or not from nurses not involved in the study during audience discussion. I feel confident that the records I have kept in my reflexive field notes of these events identifies there were several nurses outside of the study who considered these findings applicable to their own experiences.

Being transparent about the process of analysis is also considered to add to transferability and trustworthiness (Connelly, 2016). In section 4.6. I highlight how I approached my analysis, how I judged data saturation, and what influenced my choices and interpretations, adding to the transferability of the findings.

4.8. Chapter conclusion

In this chapter I described how I conducted my study. I have discussed how I engaged with stakeholders in designing the study and their role in acting as advisors. I described how I identified and addressed ethical issues and obtained ethical approval and provided details of recruitment procedures. I presented my approach to recruitment and have provided demographic characteristics of the hospital and care home sites and hospital and care home nurses participating in the study. I described my methods of data collection, (focus groups and interviews) and the approach I used to analyse the data, qualitative content analysis. I described how I aimed to provide a transparent process, sharing content of my reflexive notes, acknowledging my insider position and the impact this has on how I have conducted the study. I discussed the steps I have undertaken to enhance the quality of the research. In the next chapter I present the detailed findings from the qualitative content analysis.

Chapter Five: Findings

5.1. Introduction

In this chapter I present the answers to first research questions in the study.

1. *How do hospital and care home nurses describe their role in providing care for people living with dementia who return to their care home after a hospital stay?*

The findings to the second research question and a synthesis of the findings, presenting four themes relating to nurses' roles are presented in chapter six.

Hospital and care home nurses describe four roles:

1. Exchanging information
2. Assessing and meeting physical and psychological needs
3. Working with families
4. Checking and organising medication.

Each of these four roles include nursing activities. I have organised the results by presenting these nursing activities with reference to the four phases of the transition pathway (Waring et al., 2014).

1. Admission to hospital,
2. While in hospital,
3. The day of discharge,
4. After discharge.

It was notable that hospital nurses referred to the person living with dementia as 'patient' and care home nurses referred to them as a 'resident'. I have mostly adopted the term 'person with dementia' when reporting the findings unless it has specific resonance to the context of hospital or care home. Prior to presenting the findings, I first describe how I selected the quotations and reflective notes used to illustrate the findings and secondly, the rationale for using frequencies in reporting nurse perceptions.

5.1.1. Use of frequencies and judging strength of opinion in reporting nurses' perspectives.

Braun and Clarke (2013) argue that flexible data collection tools, such as interviews, mean that not every participant will discuss exactly the same issues, and that if someone does not discuss something it does not necessarily mean they do not have an opinion about the issue. Consequently, there is much debate about reporting frequencies to describe a pattern generated from qualitative data. Braun and Clarke (2013) do not support using frequencies because of the complexity of qualitative data, recognising that even if only one or two people discuss something the point may still be significant. However, to indicate the strength of nurses' agreement about perceptions of the nurses' role, I have provided some quantity related language similar to that used in an example by Terry (2010) (cited Braun and Clarke, 2013:108). I use the words 'most' 'many' and 'majority' to mean over half of the sample, 'several' refers to about half of the sample and 'few' or 'some' around a quarter or less. If nurses' views are absent on a particular issue this is highlighted.

I examined not only how often nurses discussed a particular issue but also listened to the way nurses talked about the topic. I observed the emotions expressed, for example frustration or anger (recording these at the time of the interview or group as reflective field notes) and I made judgements about the significance of issues discussed. I also examined the research context of discussion, for example, if a topic of discussion was aired within a group or dyadic interview, this may have led to some further insights about the topic due to the conversational processes between participants. I made decisions about the significance of these issues discussing and confirming interpretations with my supervisors. When using quotes, I indicate the context; interview, dyadic interview or focus group.

Frequencies, emotive discussions and my reflections contributed to judgement about categories and themes obtaining meaning saturation. I judged most of the themes and categories to be saturated and I have indicated where I considered saturation was not achieved and where this should be further explored.

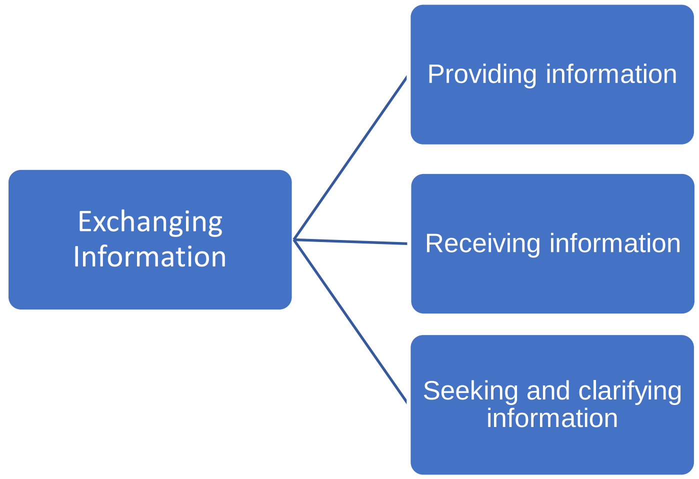
5.1.2. Selection and use of quotations and reflective notes.

I use anonymised participant quotes and my own reflective notes to illustrate the findings. Using quotes within qualitative papers is expected practice (Eldh, et al., 2020) but authors report little attention is paid to the use of them, for example their purpose and how they were selected (Cordon and Sainsbury, 2006, Eldh, et al., 2020). Cordon and Sainsbury (2006) found quotes are used for several purposes such as providing explanations, enhancing readability and as evidence to strengthen the findings. Furthermore, Lingard (2019) suggests that quotes should be illustrative of the point the writer is making, represent the patterns in the data and should be distributed across most participants. Quotes therefore should be strategically selected (Thorne 2020). I have aimed to use participant quotes which illustrate key points but also represent the meaning within the category or theme. I have also made efforts to ensure they are distributed across both hospital and care home nurse participants. This has meant that I have not always used the best examples and have resisted the temptation to just use quotes from those who provided the most colourful or succinct quotes. Throughout all the three findings’ chapters, I have used at least one quote from each participant.

Some of my reflexive field notes (taken at the time of shorty after the interview or group or my observations from discussions with audiences), have also been included to strengthen the findings.

5.2. How do hospital and care home nurses describe their role in providing care for people living with dementia who return to their care home after a hospital stay?

5.2.1. Exchanging information



I will report on the three information exchange activities which hospital and care home nurses described as part of exchanging information: 1) providing information, 2) receiving information and 3) seeking and clarifying information. How these activities were conducted varied between wards and between care homes. It was evident that hospital and care home nurses had an interdependent role in exchanging information. A nurse emphasised the importance of exchanging information in order to ensure a safe transition.

> “***It’s in the best interest of the patient that we make sure the care home has got the information that they need to make sure it’s a safe discharge”***

(P33, intermediate care, Hospital B, individual interview).

5.2.1.1. Providing information

In this section I report on hospital and care home nurse perspectives of the different methods used to provide information. Nurses described using a variety of written records and different verbal exchanges including ‘in person’ discussions and phone calls. The information exchanged centred on the person living with dementia, their history, needs and transfer plans. I describe to whom nurses provided this information to and where on the transition pathway. Table fifteen provides an overview.

Table fifteen

When	What information exchanged	How communicated	Who to whom
Admission	About person's– biography, likes and dislikes, escalation of health record. DNCPR, DOLs. Medication.	Red bag Person's passport Hospital pack In person with CH staff member.	CH – H (Care home nurse to hospital nurse).
While in hospital	Person with dementia (health) progress and (medical) treatment.	Telephone In person with CH staff member.	H- CH CH- family CH – H.
Day of discharge	Communication needs, behaviours, nutrition, medication, activities of daily living and skin integrity. Treatment provided while in hospital. Information from each professional involved. Follow up care recommendations.	Nurse to nurse record Copies of nursing assessment A medical discharge summary Multi-professional discharge summary Red bag Verbal handover.	H – CH.
After discharge	Health care needs, how to meet them.	Discharge letter Telephone call.	H – CH.

At admission

Care home nurses from three of the four care homes discussed a structured system for providing information to the hospital when a decision had been made to admit the person living with dementia to hospital. While each home used a different system for providing information, similarities were described in that they were electronic forms which were completed and printed off and included person-related information,

> ***“We’ve got policies in place when somebody does go to hospital, like we send them with almost an emergency pack, don’t we, of standard information that a person might not be able to communicate because of their dementia. Pink passports, which have got demographics and an overview of their needs”***

(P21, focus group, CH4).

Most care home nurses from each of the three care homes said it was important for enabling hospital nurses to provide personalised care to people living with dementia. Nurses who stressed this aspect had received dementia care training.

All nurses from one care home mentioned they used the ‘red bag scheme’ for providing information. The scheme is described in 1.4.2. One nurse described how they used it,

> ***“And we have varying forms that we complete with as much information as possible. [ ] so an escalation*** **(health needs)** ***record [ ] a full assessment form which tells you anything and everything about the resident, the*** **DNACPR (do not attempt cardiopulmonary resuscitation)** ***or advanced care plans, anything to do with DoLS*** **(deprivation of liberty safeguards)** ***the ambulance also have to sign to say they’ve got the lovely red bag, the hospital are supposed to sign and the ward”***

(P7, unit manager, CH2, individual interview).

Another nurse from the same care home added they also included the *‘resident passport’* which she described provided a biography of the person. Overall nurses from these three care homes described providing comprehensive written information to the hospital nurse when the person living with dementia was admitted. These reported practices were not associated with the quality rating of the home. Each of the three care homes had different quality ratings: requires improvement, good and outstanding.

Some care home nurses from the same three care homes also described how, at times, sending a member of care home staff with the person living with dementia to the hospital was one way to provide information verbally,

> “***This is why I like to send staff…help sort of the transition, we can talk to the nurses and pass on as well as the handwritten, verbally pass on information”***

(P10, care home nurse, CH2, individual interview).

At least one hospital nurse discussed the value of speaking with care home staff who accompanied the person to hospital. They considered the care home staff as being able to give comprehensive information about the person living with dementia. However, some nurses from both hospital sites indicated it was not routine for care home staff to accompany people living with dementia when they were admitted, highlighting variation in care home nurse practice.

While in hospital

Several hospital nurses described responding to care home nurse requests for information about the person’s progress and treatment while the person living with dementia was in hospital. Both hospital and care home nurses mentioned this was not proactively provided by hospital nurses. A senior hospital nurse considered it to be *‘the care home nurses role’* to request this information. Most nurses from all the care homes saw this as their role and said they performed it daily whilst the person was in hospital. However, the majority of care home nurses and several hospital nurses reported there were challenges in sharing hospital patient information, which included releasing information to care home nurses.

Most care home nurses mentioned the information shared during these verbal exchanges were very general, such as ***‘they have had a comfortable nigh***t’ (P4, CH1 dyadic interview). Many care home nurses attributed this inadequate level of detail to staff not being the next of kin, stating hospital confidentiality policies restricted access. Care home nurses found this frustrating,

> ***“There is usually a difficulty of releasing information [ ] I’ve had trouble with, ‘oh, we’re not giving you that information, it’s just next-of-kin to know this’. But I think we’re just as equally important to know how our resident is”***

(P22, CH4, focus group).

A nurse in each hospital explained their difficulty in releasing patient information to care home nurses. They described a system for the secure verbal transfer of patient-related information which involved establishing passwords so only those with the password could receive this confidential information. However, they explained this procedure was mostly set up for family members, because of this they interacted more with family about the person's condition than with the care home nurse. Despite having this system there were some hospital nurses who described a way they check the authenticity of the enquiry and ensure confidentiality of information is passed on,

> ***"But what we normally do, and what I guide my staff to do is, so if you've got a generalised enquiry, say from, I don't know, one of the care homes. Mrs so-and-so, yeah, she's doing well at the moment. So, then you ring them back so that you know the number and you're ringing through into the care home and you're speaking to somebody that works in the care home"***

(P28, senior nurse, elderly care ward, Hospital A, individual interview).

Other similar experiences were talked about by nurses at both hospital sites. One senior nurse mentioned it was easier sharing information with the care home nurses with whom they already had a relationship with. Although most care home nurses mentioned the difficulties in obtaining resident related information, there were some hospital nurses who recognised that care home nurses should have access to this information. Notably these hospital nurses either had a senior role or had over ten years of experience.

Day of discharge

On the day of discharge, hospital nurses provided both written and verbal exchanges of information. There were different systems for communicating information at each hospital site. At Hospital B, all nurses interviewed referred to a 'nurse to nurse' record which was completed by a nurse with lead responsibility for the discharge. This record had been specifically designed for patients discharged to care homes. Hospital nurses said this form highlighted communication needs, behaviours, nutrition, medication, activities of daily living and skin integrity. In addition, nurses working in specialist wards at Hospital B also reported that they provided copies of nursing assessments for the care home nurse.

> ***“We send all our assessments, …a recent Waterlow (pressure area) we photocopy that…and any risk assessments, falls, MUST (nutritional assessment), catheter care plans if they’ve got a catheter in…wound care plan…they (the care home nurse) get a lot of information”***

(P13, senior nurse, orthopaedic ward, Hospital B, individual interview).

Not all nurses agreed that sending copies of nursing assessments, in addition to the nurse to nurse record was necessary. For example, a senior nurse from a short stay ward questioned how useful copies of nursing assessments are for the care home nurse, stating care home nurses would be conducting their own assessments when the person living with dementia returned. This highlights variation in practice between specialist and short stay wards.

At Hospital A, three different systems were described, ‘*a medical discharge summary’* was used on most wards, ‘a *multi-professional discharge summary’* was used on the intermediate care ward and ‘*the red bag scheme’* used if it had been provided at admission.

Hospital nurses described the ‘*medical discharge summary* ‘as a summary completed by the doctor containing information about the person’s recent admission, the treatment provided while in hospital and any necessary follow up care which was required. This was sent to the GP and with the person back to their care home. One nurse from a short stay ward described how she would ask the discharging doctor to add any significant nursing issues onto the medical discharge summary.

Hospital nurses from the intermediate care ward at this site described a ‘*comprehensive multi-professional discharge summary’* of medical information, allied health professional assessments and various nursing assessments that had been undertaken. These nurses described preparing hard copies of these assessments sending these with the patient when they were discharged back to the care home.

Hospital nurses from both hospital sites also discussed completing the discharge paperwork contained in the red bag, if the care home was using this scheme. A senior nurse from Hospital A acknowledged that because not every care home was using it, there were different methods for providing information and in her view, this was not ideal.

A few hospital nurses at both sites described a '*verbal handover* 'given by hospital nurses to care home nurses at discharge. There was variation noted in the detail of the '*verbal handover'* and when it happened. A senior hospital nurse mentioned despite sending a written '*multi-professional discharge summary'* this verbal handover which included a detailed discussion about the care needs of the person was important. It was described as '***belt and braces'*** and '***all about good communication'*** (P16, senior nurse, intermediate care ward Hospital A, individual interview).

However, another nurse implied their handover to care home nurses could be better, particularly when comparing it to hospital nurse handovers,

> **"*We take patients from other wards in the hospital and we would never accept a patient, without a nursing handover, and they'll tell you everything and the needle to the thread, and, even though it's all there in front of you on the screen, cause we're on the computer now, but when we send people home back to nursing homes, the conversation that you have with the care home is very brief, and that nursing handover doesn't really happen*"**

(P29, elderly care ward, Hospital A, individual interview).

A similar discussion with a nurse at hospital B identified their handover about catheter care to district nurses was more comprehensive to what they provided to care home nurses. A disparity was noted in what information is provided to other nurses in the healthcare system to that what is provided to care home nurses.

Hospital nurses described differences in the content of verbal information provided to care home nurses depending on the type of ward they worked at. For example, several nurses working on short stay wards said they made verbal contact with care homes primarily to notify them of the discharge and that it would be happening that day. Hospital nurses explained that discharge decisions happened quickly because of an ***'increase demand for bed capacity'*** *(*P14, senior nurse, medical unit, Hospital A, dyadic interview***).*** The verbal handover about care needs was described as *a 'brief overview'*. They implied there was little time to give care home nurses notice and a detailed handover.

There were a few hospital nurses at both sites who expressed the importance of collaborating with care home nurses early about discharge keeping the lines of communication open between them throughout the stay. Notably, it was only nurses working on the specialist wards who discussed this. Hospital and care home nurses relied on each other for providing information about the person's needs so they could each provide optimal nursing care throughout the transition.

5.2.1.2. Receiving information

In this section I report on hospital and care home nurse perceptions of the information they receive when the person living with dementia is transferred from one setting to another (whether at admission or at discharge). The variation in quality of information received is highlighted.

At admission

Although care home nurses from three of the care homes described sending comprehensive information at admission, most hospital nurses commented that information provided by care homes varied enormously. Two senior nurses from Hospital B mentioned care home residents with advanced dementia having been admitted to their ward without any information about them provided by the care home. Similarly, several nurses at Hospital A stated there was sometimes a lack of written information from care home nurses about the person's needs. They mentioned this was particularly problematic in cases of people living with dementia who were unable to communicate their own needs.

There were discrepant perspectives amongst several hospital nurses about the efficacy of the *red bag scheme*. There were senior nurses at both hospital sites who said it had improved information exchange with care homes. Conversely, a nurse from Hospital A shared an example where the red bag had been used to carry in the person’s belongings, but the care home nurse had not completed the paperwork.

A few care home nurses described when their resident was admitted, they frequently received calls from hospital nurses requesting the same information that had already been sent in with them. They were frustrated that hospital nurses were not reading this information.

While in hospital

Most care home nurses discussed how they were informed about the discharge of the person and how this varied. Nurses from three care homes mentioned there were occasions when they received verbal notification in advance of discharge, up to the day before. However, several nurses from all care homes said they were frequently given insufficient notice discharge was taking place.

During audience discussion at a nursing conference where I presented my findings, this was also acknowledged as a common issue.

At discharge

A few care home nurses in each of the four care homes mentioned that the information they received from hospital when the person was discharged varied in content.

> **“P2: It differs a lot from ward to ward in the hospital, some people are very careful with…**
> **P1: yeah with what documentation they send, with what medication they send, and others….**
> **P2: It varies so we cannot put them all in the same… ”**

(Focus group, CH1).

Most care home nurses from each site commented that discharge paperwork they received from hospital was often incomplete and brief. Two nurses from two care homes mentioned there had been occasions when they had not received information that their resident was being discharged.

After discharge

A few hospital nurses were critical of how the receiving care home nurse engaged with the information provided when the person was discharged. There was a nurse from each hospital site who mentioned it was not unusual to receive calls days after the discharge of the person, with a request for further information,

> ***"You get somebody that's gone home say two days ago [ ] 'Oh, I'm just ringing up because I've just noticed this on the discharge letter, could you explain it to me?' But then the notes have gone then. And I always sort of like think, I'd like to think they was reading the discharge letter the minute they got them back to the care home, and then suddenly two days later, 'well I've just noticed this on the discharge letter'***

(P30, elderly assessment ward, Hospital B, individual interview).

It was implied there were variable practices and variable quality of information received when care was transferred from one setting to another, which was a source of frustration for both hospital and care home nurses.

5.2.1.3. Seeking and clarifying information

The consequences of inadequate information exchange resulted in both hospital and care home nurses seeking further information or clarifying information which was not clear. The variety of ways nurses seek to obtain this information is presented.

At admission

Several hospital nurses from both sites mentioned they would need to contact the care home nurse to clarify information about the person's needs at admission, particularly if little or no information had been sent with them. A few hospital nurses raised the problem of accessing the right person to talk to at the care home. One nurse mentioned that sometimes when she called a care home, she would receive a response '***I'm bank staff*** '(P13, orthopaedic ward, Hospital B, individual interview), she stated this would result in getting very little information. My reflexive field notes of this discussion indicated this was said with much frustration "*this lack of information from care homes seems to cause a lot extra work for hospital nurses, they seem rather* *irritated by it"* (Reflexive field notes from P12 and P13 individual interviews). In such instances hospital nurses described sourcing the information from past medical notes to see what they could glean from any previous admissions.

While in hospital

Most care home nurses sought information about their resident's progress when the resident was in hospital. If information was not forthcoming, nurses from two of the care homes mentioned they visited the person in hospital. This helped them understand the person's care needs so they could make plans for their return,

> ***"We do go and visit them as well whilst they're in hospital so that's sort of an opportunity to see how they're getting on and speak with the staff there. sort of see what's happening there and how they're dealing with things"***

(P18, Team leader CH1, individual interview).

Other care home nurses mentioned contacting resident's families to seek such information.

Day of discharge

Care home nurses mentioned they had to telephone the hospital nurse to clarify information if brief or incomplete discharge information was received on the day the person returned to the care home.

> "***Yes, there may be something which is not well, clearly written down. So, we always ring them back and ask about it. Sometimes, you know, like the catheter or something, they mention catheterised, but they don't say when it's catheterised. There are a few things like that"***

(P19, CH1, individual interview).

A few care home nurses mentioned that obtaining this information was not always straightforward. One nurse discussed challenges in getting through on the telephone and speaking to the right person in the hospital. She was often reliant upon the hospital nurse returning the call and sometimes there was a delay meaning she would often have to *'chase'* for the information.

There were two care home nurses from different sites who mentioned they could not access hospital electronic records even though other community-based healthcare professionals could. I have noted from my reflective field notes and listening to the tone of the recordings that these nurses were annoyed that the electronic systems which could support exchange of information were not *'joined up'* and that care home nurses were excluded from accessing them. A few hospital nurses at one site also mentioned that access to a shared electronic record would help with information exchange.

Summary of exchange of information

Exchange of information was discussed by all nurse participants and was identified as a major role. The three sub-categories, providing information, receiving information and clarifying information were judged to be important nurse activities that were discussed by the majority of both hospital and care home nurses. I noted there was often emotive discussions about the quality of information exchange and the topics were reiterated.

Hospital and care home nurses generally agreed they rely on each other to provide comprehensive and timely information to ensure optimal nursing care at this transition. Comprehensive information exchange was seen as particularly important to meet the needs of people living with dementia who may be unable to communicate their needs for themselves.

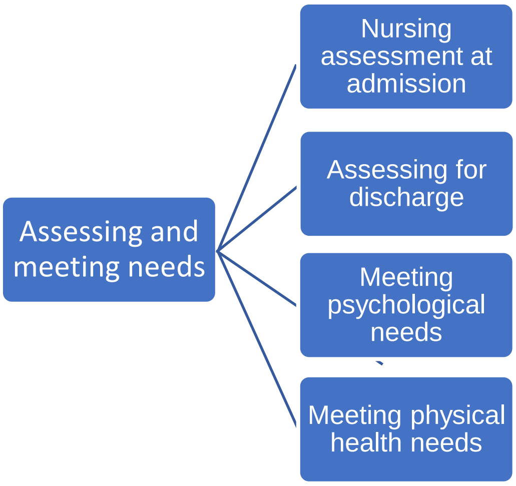
The methods of transfer were not standardised, there were different systems for communicating information and recent initiatives to improve information exchange were not universally embraced.

The comprehensiveness and quality of information varied. Hospital nurses differed on the content and timing of the information they sent depending on the type of ward they worked in. At discharge, nurses working on specialist wards sent more information and engaged earlier in notifying care home nurses. Nurses attributed the variation in content and timing to the frequent brevity of the stay and the rapid turnover of patients in short stay wards.

There was a discrepancy of perspectives between hospital and care home nurses about exchange of information. Hospital and care home nurses describe comprehensive transfer of information, but report what they received from each other was frequently inadequate. This results in extra work for both hospital and care home nurses who described having to seek additional and clarify information.

Most care home nurses report being excluded from accessing hospital records of their care home residents. Some hospital nurses recognised there were disparities in the comprehensiveness of information they provided to care home nurses compared to that of other nurses in the health care system, in that they shared more information with district and other hospital nurses

5.2.2. Assessing and meeting physical health and psychological needs



Hospital and care home nurses discussed assessing and meeting both the physical health and psychological needs of the resident at all phases of the transition pathway. The role is comprised of four activities: 1) conducting a nursing assessment at admission (in hospital and at care home), 2) assessing for discharge, 3) meeting psychological needs and 4) meeting physical health needs.

5.2.2. Conducting a nursing assessment at admission

This section describes the different assessments that hospital nurses conduct when the resident is admitted to hospital and includes how they identify the specific needs of people living with dementia. Care home nurses also conduct assessments when the person living with dementia returns to the care home following hospital discharge.

<u>At admission</u>

Hospital nurses discussed conducting a nursing assessment when the resident was admitted to hospital. Many hospital nurses viewed identifying the psychological and physical health needs of the resident was crucial when the resident is first admitted. One hospital nurse reported that a thorough and accurate assessment at admission facilitated discharge planning and the smooth discharge out of hospital,

> ***"I think our main thing is that if you do the admission assessment correctly it always facilitates a smooth discharge...and if you can identify what that person's needs are when they come in, obviously you can anticipate any changes during the process while they've been here and then you, you can identify them when they leave……, the questions around discharge I think should come up early on in the admission"***

(P29, elderly care ward, Hospital A, individual interview).

The majority of nurses from both hospitals discussed how this assessment at admission included obtaining a baseline of the resident's needs, their normal level of functioning and some background history. They articulated their aim was to plan what input the person would need to get them back to, or as close to, that baseline of health and function: to a point where the care home nurse could continue to meet their care needs. They discussed liaising and working with allied health professionals such as physio and occupational therapists in meeting these aims. Notably nurses discussing these baseline assessments were from specialist wards where people had a longer length of stay.

A few hospital nurses at both sites discussed the use of nationally recognised dementia-specific assessment and care planning tools that assisted them to understand the unique needs of people living with dementia. Two tools were described and further details of these tools can be found in section 1.4.1. At Hospital B, most nurses either described the use of '*patient passports'* which were brought in with the person on admission or '*butterfly care plans*'. Hospital B had adopted '*The Butterfly scheme'*. One nurse from this hospital mentioned activities involved encouraging these care documents to be completed with either care home staff or the family. A few nurses at Hospital A described a comparable tool, which had been designed locally, which they described as similar to the ‘*This is Me’* tool,

> ***P15: “They (This is me) should come in with them and you try to follow that,***
> ***P14: I don’t see a lot,***
> ***P15: No, you don’t”***

(Senior nurses, dyadic interview, elderly care and medical unit).

Only three nurses from this hospital discussed the use of the ‘*This is Me*’ tool suggesting their use was not widespread and that care practice varied.

On return to the care home

Several nurses from all four care homes said they conducted a nursing assessment of the person when they were readmitted back to the care home. Nurses from two care home sites gave illustrations of health assessments such as monitoring blood pressure, mobility, body maps (identifying bruising and wounds), in addition to assessments of activities of daily living. Many of the nurses from all care homes discussed ‘*checking for changes’*, reassessing how their care needs had changed since admission,

> ***“If there were any changes in their eating and drinking pattern, in their mobility, things like that, when they come in again, we need to assess all that again we have to assess every time the resident come back from the hospital really”***

(P11, CH3, individual interview).

Four care home nurses participating in a focus group discussed a nurse conducting regular observations during the first night of a person’s return, to assess the level of night care the person required. They had been informed by the hospital that this person had a higher level of night care needs than when they were last in the care home.

Two nurses from one care home independently stated how the health needs of a care home resident can change in transit. They mentioned that residents could sustain skin injuries if they have a had a long journey or experienced a significant wait for the ambulance. As such, they needed to compare the information sent from the hospital such as body maps with their own assessment.

5.2.2.2. Assessing for discharge

This section describes the various ways hospital and care home nurses are involved in assessing the discharge readiness of the person living with dementia.

While in hospital

Hospital nurses varied in how involved they were in assessing whether the person living with dementia was ready to be discharged. Hospital nurses who worked on specialist wards, those in a senior role or who were very experienced were more likely to report active participation in assessing for discharge and in discharge decision making. Nurses from a specialist care ward discussed a team approach.

> "***We (the team) decide when we feel that the patient have reached their potential, [ ], and the patient will be better in their care home environment wherein the patient, especially people living with dementia, are more comfortable with people that they are already familiar with"***

(P32, intermediate care ward. Hospital B, individual interview).

In contrast, junior nurses working on the short-stay wards described decisions being made by the doctor on the daily ward round. However, a senior nurse working on a short stay ward mentioned voicing concerns and delaying discharge if they felt it was not appropriate or safe,

> ***"I've had a discussion with a consultant who he felt they*** **(the care home resident)** ***should go back and I, and I've just not sent them back…… er, because I didn't think that they were medically quite well enough to go back. And in hindsight my decision was correct, because the patient ended up staying in for another week"***

(P8, medical unit, Hospital B, individual interview).

Additionally, senior and junior nurses who had many years of experience, from both short stay and specialist wards discussed intervening if they considered discharge was unsafe or inappropriate. For example, if they considered discharge was not in the best interests of the person living with dementia that day because it was already late, they deferred it to the next day. My reflexive field notes taken after two individual interviews on the intermediate care ward at Hospital A also indicated this.

“*The two staff nurses have been qualified for several years and seem very experienced. They spoke with confidence and were assertive. They were not afraid to speak up to managers if they did not feel a discharge was appropriate. They quoted the NMC code and their accountability I am thinking perhaps there might be a link with confidence and experience in role”* (Reflective field notes from individual interviews P26 and P27).

Several hospital nurses working mostly on the specialist care wards discussed involving care home nurses in assessments for discharge. This included discussions over the phone or by inviting care home nurses to come to hospital to conduct their own assessment. A few nurses mentioned contacting the care home nurse to ascertain their ability to provide after care for the person. One hospital nurse raised the importance of finding out from the care home nurse whether they were able to meet the person’s goals beyond discharge. He used and discussed his interpretation of the terms ‘*medically fit* ‘and ‘*medically stable’* and noted that sometimes care home residents were discharged described as ‘*medically stable*’ back to care homes. This meant they would still require some specialist nursing care.

Some hospital nurses mentioned the care home manager or care home nurse were invited to come to the ward to see the person, talk to hospital staff, to assess the person’s needs and that they were able to view their care records. It seemed care home nurses were given access to hospital care records when they were invited to make an assessment but were unable to access them at other times.

> ***“We will ask them ‘Are you willing to take or are you wanting to reassess the patient?’ Some of the patients they won’t take without a reassessment [ ] if they have changed”***

(P31, staff nurse, acute elderly assessment, Hospital B, individual interview).

This was the only example discussed by a nurse working on a short stay ward. Hospital nurses working in intermediate care wards provided most examples of inviting care homes nurses to conduct their own assessment. Two hospital nurses mentioned that if the care home nurse did not respond in a timely manner to these invitations to assess, it could result in a delayed discharge. One nurse from the intermediate care ward added in her view these assessments were unnecessary and that the care home nurse should trust the hospital nursing assessment.

A few care home nurses from three care homes also discussed these hospital-based assessments. Some mentioned they occasionally conducted them. One example was shared by nurses participating in a focus group,

> " ***I went the other day to see a patient who was already here*** **(previously in physical health care unit)*****, and to assess him to come back to our unit*** **(specialist dementia unit)*****, because he was being aggressive"***

(P3, CH1, focus group).

Care home nurses who discussed conducting their own assessments said they valued these opportunities because it helped them to prepare for meeting the person's needs on return. Although care home nurses found it helpful to reassess their resident in hospital, many added that in reality, re-assessments did not happen. They mentioned discharge decisions were made too quickly for care home nurse assessment to take place and required the ward informing them in advance of changes in the person. This was problematic for care home nurses as they highlighted that if they were not involved in early discussions about discharge plans, they were not fully prepared to receive the person. For example, if equipment were required this could not always be instantly obtained, and this compromised their ability to provide safe and effective care. Care home nurses expressed frustration at this frequent lack of involvement in decisions about discharge,

> "***I think yeah, I think that's one of the bug bears sometimes with discharges, not knowing who's gonna come through the door, you know, in terms of their needs, what are we going to need to do, what are we gonna, you know, to keep that person or even other people safe"***

(P21, focus group, CH4).

Following a presentation of these findings at a national nursing conference, this finding appeared to resonate with the audience, who also discussed how care home nurse involvement in discharge planning was often lacking.

5.2.2.3. Meeting Psychological needs

In this section I present the activities that hospital and care home nurses described to meet the psychological needs and minimise distress of the person living with dementia when the person was admitted, was in hospital and after they returned to the care home.

Hospital and care home nurses highlighted that people living with dementia were easily distressed by a move out of their usual environment. I report three ways nurses sought to minimise this psychological distress: 1) minimising length of stay, 2) providing one to one care and 3) tailoring care.

5.2.2.3.1. Minimising length of stay

Several hospital nurses at both sites discussed how '*facilitating an early discharge*', '*minimising length of stay*', '*reducing admission time'* were a major aim when caring for people living with dementia. Nurses explained that the longer a person with dementia was in hospital there was an increased risk of further problems developing, such as obtaining infections. One hospital nurse who was a 'dementia champion', reported that minimising length of stay was in the person's best interests,

> ***"a person with dementia is out of their comfort zone when they're in hospital, probably quite frightened, probably displaying lots of characteristics that probably isn't necessarily normal for them because they're frightened. Um, they don't know any of us, it's a strange place, um, so you want to get them back to where they're happy and feel safe"***

(P27, intermediate care ward, Hospital A, individual interview).

A few care home nurses from two sites shared hospital nurses' priorities of minimising the length of hospital stay for the person living with dementia. Care home nurses said they liaised with the hospital nurses about arranging for the person to be discharged as soon as possible, particularly if they had heard that the person was distressed by being there.

5.2.2.3.2. Provide one to one care

At admission

Several care home nurses at two of the care homes mentioned they routinely accompanied the person living with dementia when they were admitted to hospital. One care home nurse mentioned they would stay with them until a family member could take over to provide one to one support.

While in hospital

A few nurses from both hospitals described people living with dementia as often being ‘*unsettled’* or ‘*agitated’*. Two hospital nurses described people living with dementia who displayed ‘*aggressive behaviour’*, which they were required to respond to. At Hospital B, nurses discussed ‘*close monitoring’* of distressed patients, which involved providing one to one care which they referred to as ‘*enhanced care’*. No nurse interviewed from Hospital A described the use of ‘*enhanced care’*.

Nurses from two care homes mentioned that they sometimes provided one to one support to people living with dementia while they were in hospital. These two care homes had been rated as good and outstanding. They identified challenges in how distress was responded to in hospital. They described care home nurses were not able to fulfil their role in the way they would normally, due to hospital policies and procedures being different to what they were used to in the care home setting. For example, the use of restraints was described as more acceptable care practice in hospitals than care homes. They highlighted potential issues about duties of care,

> ***“I think, when we take our residents to the hospital, the moment that they’re admitted it’s, that’s where our duty of care has to take a step back, 'cause somebody else has taken accountability of her [ ] And that’s where it’s difficult because I think quite often they*** **(Hospital staff)** ***encourage our… they want… our staff to stay at times when people are more heightened, but we, are not always, you know, maybe not always able to kind of enforce our policies. If somebody wanted us to use,***

> ***let's say, restraint, for example…[ ] we can't be doing that...we don't in the community do it like that"***

(P20, focus group, CH4).

In my reflexive field notes from individual interviews undertaken at CH2 and CH1, I noted that care home nurses perceived that hospital nurses found it difficult to respond to distressed care home residents living with dementia. Several mentioned that one-to-one care was required and that admissions should try to be avoided where possible.

"*It does seem that care home nurses are very aware of the challenges that hospital nurses have in looking after residents with dementia. Several references to avoiding admission*" (Reflexive field notes after individual interview P10, CH2)

*"Again several references that residents need one to one in hospital and that family members want the resident to come back as quickly as possible" (*Reflexive field notes after focus group CH1 and dyadic interview participant P4 and P5)

After discharge

Nurses from each care of the four care homes discussed activities they engaged in to '*settle*' the person when they arrived back from hospital. Several care home nurses mentioned people living with dementia in particular could be unsettled and disorientated on return from hospital. Care home nurses explained there needed to be a period of '*re-orientation'* for the person and described assigning members of staff to be with the person to '*settle them in'*. One care home nurse remarked assigning one to one care enabled her to understand the specific needs of the person, and how they might have changed since admission to hospital.

5.2.2.3.3. Tailoring care

In this section I report on hospital and care home nurse perspectives of how they tailor care to meet the individual needs of people living with dementia.

At admission

A few hospital nurses and several care home nurses stressed the importance of knowing the person's biography. They mentioned this was particularly important for people living with dementia, to help get to know the person,

> ***"Well, their biography, that's very important. If you send a resident with dementia without any details, they will struggle, the hospital also will struggle. They need to know each bit about that resident, otherwise they will, their mood will get changed and the hospital staff won't know what are the things that can keep that person calmed down"***

(P6, CH2, individual interview).

<u>While in hospital</u>

Several hospital nurses discussed '*tailoring care'* or developing strategies to minimise the person's distress. Several hospital nurses mentioned knowing the person living with dementia was important to provide an individualised response. A nurse who was a 'dementia champion' gave an illustration of the importance of how knowing the person helped with gauging the timing of communicating with them,

> ***"It's about knowing your patient really. It's about understanding what they respond to. Some people might need preparation,*** **(involving in discharge planning)** ***some people might not need preparing……. because often people with dementia can get very anxious. If you tell them too much information in one go or, you know, too much in advance, they've got many days to worry about it. [ ] So, it's about knowing your patient and working out really what's best for them [ ] and sometimes advocating for them"***

*(*P16, senior nurse, intermediate care ward, Hospital A), individual interview).

Individual tailoring to involve people living with dementia in their care was raised by a few hospital nurses at both sites. Although no nurses raised the use of formal assessments of mental capacity, nurses described that the amount of information given to the person living with dementia was dependent on the person's ability to understand and retain information. This indicated informal assessments took place and decisions were made based on this. In contrast, there were discrepant perspectives on engaging with the person living with dementia. There were a few nurses who mentioned that despite the person being unable to retain information, it was still important to engage and inform them that they were going back to the care home.

> “***Well, we generally, we tell them that they’re going back home, but nine times out of ten they might have forgotten [ ] then obviously we just remind them again when the ambulance crew come, that you’re going back to the care home, which is your home”***

(P30, acute elderly assessment ward, Hospital B, individual interview).

Hospital nurses discussing this more standardised approach worked on short stay wards, where it was more difficult to know the person as they would only be in hospital for very short periods of time.

Day of discharge

Hospital and care home nurses differed in their level of involvement with discharge. Hospital nurses described more activity and they described the day of discharge as *‘busy’* and could be particularly challenging for a person living with dementia, because they may have to wait for long periods for discharge arrangements to be made. Nurses working at both hospitals and across all wards described different strategies they might use to minimise or respond to distress on the day of discharge. They mentioned using distraction techniques, providing some activity or a comfort item such as a favourite photograph. One hospital nurse also described a particular accommodation she made for people living with dementia who were able to remain in their bed area whilst waiting to go back to their care home. She explained that it was usual practice for other patients to be asked to vacate their bed area and wait in the ward lounge to enable nurses to prepare the bed for the next patient. However, she considered this practice potentially disruptive for people living with dementia.

Several hospital nurses from both sites discussed tailoring the arrangements for transporting the person back to the care home. They discussed that making decisions about the type of transport for the person with dementia required careful consideration, particularly if they had required one to one support while in hospital.

> ***"It's our clinical judgement in how we want that patient to get safely…I mean there's no point, if we've been*** **giving** ***enhanced supervision a patient in the hospital, there's no point us saying, we'll have a T1, which is just a sit… a, a one person ambulance, well a one-manned ambulance and a chair"***

(P12, senior nurse, orthopaedic ward, Hospital B).

Most nurses at Hospital A arranged for people living with dementia to go back to the care home with a *'two-man crew'* (driver and escort). Nurses at Hospital B described arranging a '*private ambulance or taxi'* which offered some flexibility. They said this could prevent patients having to wait long periods of time for hospital transport, but they could not arrange this as a matter of routine.

Two senior care home nurses from one care home also discussed the journey back to the care home for the person. They highlighted that people living with dementia were vulnerable during transportation between care settings and that journeys could sometimes be long and have a negative impact. They mentioned they would like to have a greater role in providing transport or escorting their resident back to the care home.

Several nurses at both hospitals described the majority of patient journeys used shared transportation when several patients were taken home at the same time. This meant the person may not experience a direct journey, but rather one which was potentially long and disorientating. One senior hospital nurse described intervening if she considered a patient would be distressed by a journey. She would make a special request to the transport crew to allow the person to have a direct journey home. Furthermore, a senior nurse of the intermediate care ward explained they had a separate transport contract from the main hospital. This ensured transport was always for a one person's journey. This was in recognition to minimise journey times and prevent distress.

Not all nurses interviewed discussed organising transport in detail but for those who did it was clearly important for preventing distress and seen as the province of senior staff.

Several care home nurses from two care homes mentioned that the timing of discharge could influence the psychological needs of people living with dementia. They explained that for people living with dementia, evening could be a difficult time, being moved late in the evening or night could add to their distress. Nurses at two care homes mentioned incidences of residents arriving from hospital late. One of the care homes operated a policy which stated that no new admissions or discharges from the hospital to be accepted after 5 or 6pm. Several hospital nurses mentioned there were many other care homes who operated this policy. Many hospital nurses mentioned this policy resulted in the patient having to stay an extra night in hospital and these nurses found this frustrating. The policy contributed to a tense relationship between hospital and care home nurses,

> ***"And sometimes as the day goes on - and it doesn't matter whether it's winter or summer. The doors shut at 6 or the doors shut at 7, And I've turned round and said, so you're telling me if I put my mum in your home you would tell me that I would not be allowed to take her out for the day and, if I couldn't get her back by 7 o'clock you are not going to let my mum back in her home. Is that what you're telling me? Oh, but that's different. No, it's not different"***

(P15, senior nurse, dyadic interview, elderly care, Hospital A).

Not all hospital nurses shared this lack of understanding of why this policy had been developed. There were a few hospital nurses who expressed empathy that a late transfer back to the care home was not conducive for people living with dementia. They appreciated it would take time for the care home nurse to help '*settle*' the person and re-establish their routine. Nurses at the care home who operated the no evening readmissions policy mentioned they would often enforce it to prevent late transfers back to the care home.

5.2.2.4. Meeting physical health care needs

The physical health status of people living with dementia in care homes was raised by both hospital and care home nurses. One hospital nurse mentioned they were ***'very complex patients'*** (P29, elderly care ward, Hospital A, individual interview). Two other hospital nurses explained care home residents were often discharged with ongoing complex physical health care needs. Meeting these physical health needs was mostly mentioned by care home nurses.

After discharge

Several care home nurses from two sites discussed the challenges of meeting physical health care needs. They described how they relied upon hospital nurses to give them full information about the ongoing care and they required the supplies needed on discharge. For example, they needed the hospital to specify or send dressings for wounds. If information or supplies were lacking this caused a lot of stress and extra work.

> ***P2:"I tell you a recent was yesterday, your resident went to hospital and returned, and we had no information about the wound, um how do we have to care of that, when do the stitches need to come out,***
> ***P3: they don't send anything***
> ***P2: sometimes the discharge letter is very…..***
> ***P1: Brief***
> ***P2: You don't understand what is happening there (at the hospital) they (the resident) came, I was on the nursing unit with a massive pressure sore with no information, no wound care plan. No dressings, we had for days and days to chase that"***

(Focus group, CH1).

Nurses at these two care homes also discussed not always being prepared with the knowledge and skills to deliver this care. They described care home residents returning and requiring treatment being delivered through a new device which the care home nurses had not used before. These nurses mentioned they had to seek training in this within a very short period of time in order to deliver this care safely.

Five of the seventeen care home nurses in this study did not hold adult nursing registration and had specialised in mental health nursing. Mental health nurses working at these two care homes mentioned they were sometimes faced with unfamiliar nursing procedures. In contrast, there were two nurses from one care home who said it was rare that they would have procedures that they would not be able to manage, as they considered they had nurses with a broad range of skills at the care home. Few hospital nurses acknowledged that care home nurses may not have the necessary skills in place. Two senior hospital nurses working on specialist care wards mentioned they engaged in activities such as arranging for training or providing guidance to care home nurses.

When I presented these findings at a clinical network, discussion amongst the audience identified this as a common issue. A GP mentioned that their practice was involved in supporting care home nurse training in some of the care homes they visited.

Care home nurses also discussed how they ensured that follow up care appointments took place such as appointments with the fracture clinic or for blood tests. They would enter this information into their own systems and make the necessary arrangements so the person could attend. There were two care home nurses from different care homes who mentioned they would review the follow up care recommendations provided by the hospital to ensure further hospital interventions were absolutely necessary, as a journey back to hospital for a person with dementia may not be of benefit. The following quote was provided by a senior care home nurse,

> ***P9: Sometimes we question whether things are appropriate or not via the GP.***
> ***Q: Can you give me an example?***
> ***P9: .., it may be something that's …an appointment that's not particularly crucial and maybe it's quite a fair distance away, [ ] and the distress that would cause with someone with dementia to go to that appointment that might far outweigh the benefit of going there. What's going to be achieved, if it's just a check-up? Could it be done here by a***

> ***nurse practitioner rather than distressing them taking them all the way to (city) and disorientate them again and upset them"***

(P9, unit manager, CH2, individual interview).

Care home nurses from two care homes described working with other health care professionals in meeting the physical health care needs of the person when they returned from hospital. They mentioned community therapists would come to the care home to conduct ongoing therapy for residents who had been discharged from the hospital team. Such referrals had often been made by the hospital. However, care home nurses shared their frustration that they were unable to talk directly to hospital therapists or make direct referrals to community therapists. One nurse mentioned that if a referral to community physiotherapy had not occurred whilst the resident was in hospital, they would have to arrange a referral via the GP.

> ***P6:"The thing is, from hospital if they*** **(Hospital)** ***do it (*****the referral)** ***you might get a visit a bit sooner than later, but if you go through a GP it takes a while…for the community physio to come and see that patient here***
> ***Q: So you can't make a direct referral to the community physio?***
> ***P6: No. It's all through the GP***

(CH2, individual interview)**.**

This resulted in a delay for the resident in getting therapy. In contrast, hospital nurses mentioned directly referring to hospital-based therapists.

Summary of assessing and meeting needs

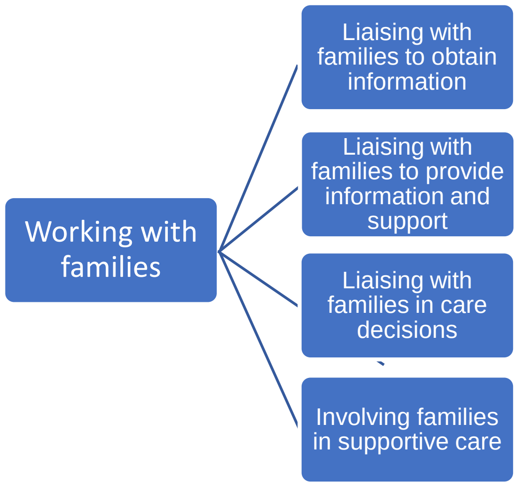
Perspectives varied between hospital and care home nurses regarding assessing and meeting needs. Several hospital nurses placed importance on an accurate assessment of the person's needs at admission to ensure optimal care when the person transitions out of hospital. Hospital nurses identified there were several stressors for people living with dementia which occurred on the day of discharge. One stressor was waiting for transport and the journey back to the care home. Several hospital nurses described arranging alternative types of transport to reduce the impact of this stressful experience on people living with dementia.

Care home nurses valued involvement in assessing the person for hospital discharge, but many said there were little opportunities to be involved. The extent to which hospital nurses involved care home nurses varied between those hospital nurses working on specialist wards and those on short stay wards. The rapid nature of discharge decision making was attributed to the lack of care home nurse involvement in discharge assessment and planning. Experienced hospital nurses or those in a senior role were more likely to seek to prevent discharges occurring if they were not in the best interests of the person or considered unsafe.

Care home residents are frequently discharged from hospital with complex health care needs. Care home nurses said they were dependent on hospital nurses to be adequately prepared to receive the person back to meet their physical health care needs. There are occasions when training is required for care home nurses, prior to the person’s discharge so that they can adequately support them. Care home nurses were excluded from directly referring residents to community-based professionals to support them with the person’s ongoing care needs.

Overall, I considered that this category and the sub-categories reached meaning saturation. I concluded this based not only on the direct findings from the nurse perspectives but used additional data from my reflective summaries and the audience discussion at two separate presentations where resonance with the findings was identified.

5.2.3. Working with families



Hospital and care home nurses discussed liaising with and involving families in the person’s care. They recognised families were an invaluable resource throughout the transition pathway and working with them was important for optimal transitions. In this section I present the activities nurses engaged in when working with families. These have been grouped into four activities: 1) liaising with families to obtain information and personal items, 2) liaising with families to provide information and emotional support, 3) liaising with families in care decisions, and 4) involving families in supportive care.

5.2.3.1. Liaising with families to obtain information and personal items

At admission

Hospital nurses said they liaise with families to obtain information about the person living with dementia. This was particularly relevant at admission in circumstances where hospital nurses received poor quality information from care home nurses and the person lacked the ability to give an accurate history. This information was reported as valuable for hospital nurses in their role in identifying person’s care needs and in completing the dementia specific care plans (Butterfly and This is Me).

A senior nurse from Hospital A said she and other nurses frequently liaised with families, often in relation to bringing in personal items for the person, so that individual needs could be met,

> “***They don’t have teeth, they don’t have glasses, they haven’t, no hearing aids, nothing, slippers and obviously that’s the first thing they’ll say, where’s my things? They’re not here, they’re at the (Care) home [ ], and then often I’ll ring the family and ask them***”

(P15, senior nurse, dyadic interview, elderly care, Hospital A).

While in hospital

Several care home nurses from each of the four care homes mentioned they contacted families when they were unable to gain information from the hospital about how the person was progressing. One nurse remarked how this was useful as it could trigger further action for care home nurses,

> ***“We keep ringing families to find out, you know, how they* (the resident) *are progressing in hospital, yeah, if we don’t get any information and family says, oh no, we visited dad and he seems to be like he’s not the same, um, then you feel like, yeah we need to get out for a reassessment”***

(P6, CH2, individual interview).

Care home nurses differed in their perspective on the appropriateness of relying on family members for information about their residents. A nurse from one care home mentioned because their residents were often with them for many years, they had built close relationships with families and family members would continue to visit the care home even though their relative was in hospital. She mentioned families would provide useful updates about how the person was progressing in hospital. In contrast, care home nurses participating in a focus group were concerned about relying on family for information. They all agreed that it was at best unsatisfactory and potentially unsafe for information to be passed via this route. Most of these nurses were mental health nurses. They mentioned that families may be stressed and in crisis and unable to take on information and relay it accurately.

5.2.3.2. Liaising with families to provide information and giving emotional support

In this section I report on the extent of liaison that takes place between hospital nurses and care home nurses and the care home resident families. The degree of involvement varies between hospital nurses and is highlighted. Care home nurse activities in communicating with families is focused mostly on giving information to them about their transfer to and from hospital.

At admission

Some hospital nurses working on specialist wards mentioned hospital admission was a worrying time for families. There were variable practices with respect to engaging with families about what to expect during their relative's hospital stay and the hospital policy regarding planning for discharge at admission. All hospital nurses at both sites said they provided families with information about their relative or their stay. One nurse explained they considered it important to provide information to the family when the person was admitted. She discussed it as normal practice on their ward to set an estimated date of discharge soon after admission.

> ***"So we, we give, on admission, it depends, we don't always give it to the patient ,it depends on their cognition, but to relatives we always give a letter that explains [ ], we know you've just got here but we're working towards your discharge. You'll be meeting all these people and at the minute this is your estimated discharge date that we're working towards. It's not set in stone, we can change it backwards or forwards depending on how you progress. So it really is a, you know, a, a discharge plan from the minute you get there really.***

(P16, senior nurse, intermediate care ward, Hospital A, individual interview).

In contrast, a nurse from a short stay ward at Hospital B mentioned that due to the *'frantic and challenging' nature* of their ward, estimating the date of discharge and communicating this to the family rarely happened.

A few care home nurses from each of the four care homes discussed contacting families about the need to transfer their family member to hospital. This could involve coordinating information, so family knew where their relative was being admitted to and when.

> **"*Family, usually we have to contact them really, when they go to hospital, we let them know that this is the reason they have gone to hospital, and we give them the updates like what time they went to the***

> ***hospital, and where they are, and which ward they are going to be admitted , things like that*"**

(P11, CH3, individual interview).

While in hospital

One senior nurse discussed how families often expressed anxiety about the changes in the person, particularly if they were more confused or had delirium in the hospital. She mentioned that hospital nurses engaged in providing advice and reassurance to the family to alleviate distress. Other examples included talking to families about any concerns they had, for example about the care their relative was receiving in either the hospital or the care home. A nurse gave an illustration of how she responded to these concerns and identified it can sometimes be difficult.

> ***P29: "if they've seen some negative things at the care home, or they might have interpreted things negatively and vice versa. So, we get a lot of stories about, oh, well they did this and they did that and, you know, [ ] We get a lot of, erm, unhappy families***
> ***Q: What do you do as a nurse then? How do you manage those tensions?***
> ***P29: It's really difficult. I think just trying to be impartial, sometimes you don't really need to do anything, you just need to let them vent."***

(Elderly care ward, Hospital A, individual interview).

The degree of family engagement varied between nurses who worked on specialist wards and those on short stay wards. Notably nurses from short stay wards at both hospitals described liaison activity which centred on giving information to the family about discharge plans. Senior nurses and those nurses working on specialist wards were more involved with giving emotional support or responding to concerns.

There were just two care home nurses from one care home who mentioned they provided information to families about the person living with dementia when they were in hospital. They mentioned they had several residents whose families did not live locally and if they were able to glean information from the hospital, they would then pass this onto the family. Several care home nurses said they knew families well and had developed close relationships with them. Yet surprisingly, no care home nurses discussed supporting families during the person's hospital stay.

Day of discharge

A few nurses from each of the four care homes described informing the family when the person returned from hospital. Some discussed how it varied in how hospital nurses informed families about the person's discharge. They mentioned there were occasions when relatives had not been informed by the hospital and so they considered it important to inform families.

5.2.3.3. Involving families in care decisions

At admission

A few care home nurses at two care homes discussed how they involved family in decisions about their relative being admitted to hospital. One care home nurse discussed it was sometimes families who preferred their relative to be admitted so they could access intravenous antibiotics, which they were unable to administer at that care home. A second nurse identified how the family were involved in a team decision about the relative's condition and potential future admission to hospital,

> "***The plan is if this happens again(abdominal blockage) she will go back in because that is, the doctor's, the nurse practitioners, the family have all discussed it and said the only thing we could do is to send her in"***

(P10, CH2, individual interview).

Nurses from one care home discussed the use of advanced care plans. They said these were developed with families of people living with dementia and the plan identified how both the person and their family are involved in decisions about treatment and admissions to hospital.

While in hospital

Hospital and care home nurses reported providing regular contact and communication with families of residents. Yet there was minimal discussion about involving families in decisions about their relative's care. These discussions were raised mostly by hospital nurses working on the specialist wards. These nurses mentioned that they invited families to multi-disciplinary meetings to discuss any specific needs regarding the person's treatment or discharge plan. Two nurses from each hospital mentioned they '*involved family every step of the way'* and arranged for families to meet regularly with consultants.

One hospital nurse mentioned family involvement varied with respect to depending on how much they wanted to be involved,

> "***I think that again, it's very individual isn't it, it depends on the person, it depends on the family, how involved are they in these discussions, because often it's not just between us and the care home, it's between us and the family and the care home, and so there's different elements that come into it"***

(P33, intermediate care ward, Hospital B, individual interview).

5.2.3.4. Involving families in providing supportive care to the person

Hospital nurses frequently mentioned people living with dementia were negatively impacted by an admission to hospital. In response to this they said they encouraged family members to visit.

Day of discharge

Hospital nurses at both sites also considered that encouraging family presence on the day of discharge was beneficial as this could be a stressful day for the person,

> ***"I think, keeping things familiar. So, I would say that a big part of what we do here, if we can, is like involve families and things [ ]. It's amazing isn't it how a familiar face can settle people sometimes***

(P26, intermediate care ward, individual interview).

In recognition that transportation back to the care home was often distressing for people living with dementia, a few hospital nurses at both hospitals discussed involving family in planning transportation back to the care home. Nurses from both short stay and specialist wards considered that for some people, family transporting or escorting the person was a better option to that of hospital transport. However, one hospital nurse indicated family liaison about involvement could take time, and this was a reason why sometimes families were not involved,

> ***"I think again we don't advocate that as much as we should and we just book transport because in some ways that's easier for us, isn't it, than ringing a son and having a big conversation"***

(P27, intermediate care, Hospital A, individual interview).

Hospital nurses from one site highlighted that not all families are able to be involved in providing transport. Two hospital nurses from different wards raised it was important to ensure the relative could safely transport the person first before arranging this.

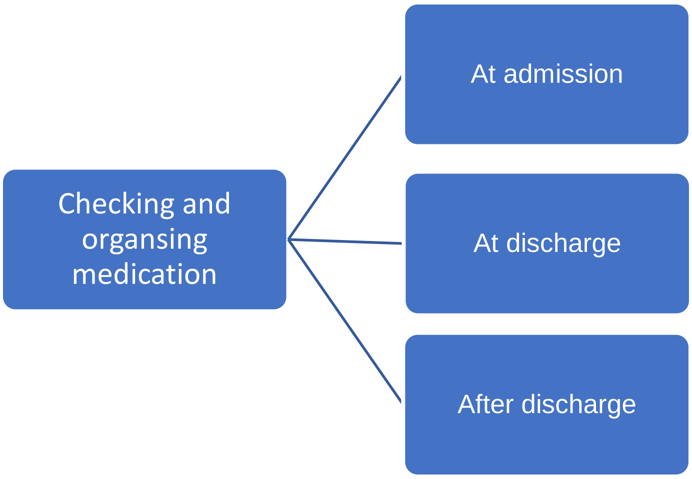
At a clinical network event where I presented these findings, the issue of families being involved in supporting the person on the day of discharge triggered much discussion. Families and hospital nurses at the event also mentioned that family involvement was often valuable in some instances but that it was dependent on individual circumstances.

Care home nurses did not discuss involving families in supportive care.

Summary of working with families

Most hospital and care home nurses who were interviewed for this study recognised and agreed that working with families facilitated optimal care of people living with dementia at this transition. Many hospital and care home nurses reported that they rely on families to support them in identifying and meeting care home resident needs. Several hospital nurses acknowledged the value of family involvement in providing emotional support to the resident particularly on the day of discharge. A few hospital nurses responded to family concerns and distress. No care home nurses described doing this. Hospital nurses varied in the extent to which they involved families in care and decisions, with nurses working in specialist wards describing a greater level of family involvement. Although I considered this category reached data saturation as all nurses discussed involving families in transitional care and it aroused strong feelings, more data could have been valuable regarding some of the topics and data saturation did not appear to have been achieved in all subcategories. In particular, care home nurse involvement supporting families was not as prevalent and may warrant further exploration.

5.2.4. Checking and organising medication



All nurses discussed roles in both checking the accuracy of medication and organising it to be available for when the person was transferred. This role took place at admission, discharge and after discharge when the person living with dementia returned to the care home.

5.2.4. At admission

Hospital nurses had different expectations of care home nurse practices with respect to medication. Hospital nurses from one hospital expected care home nurses to send medication at admission whilst a nurse at the other hospital did not.

A few hospital nurses mentioned their admission process involved them checking the person’s medication. Two nurses from Hospital A expressed strong views that medicines should be brought in with the patient and were quite frustrated with care home nurses for not sending medication,

> ***“And another big issue is nursing homes are not sending in the medication. We have people on here, they’ll be insulin diabetic, Parkinson’s, you know, and they won’t get, they’ll get their meds late every time because the nursing home, they don’t understand how***

> ***important it is, and every nursing and care home, literally everyone I ring now, I tell them ho:w important it is to send the medication***”

(P25, assessment ward, Hospital A, individual interview).

Hospital nurses further explained they could not obtain medicines immediately from the pharmacy, which was why it was necessary for care home nurses to send in medication with the person. They described that people living with dementia from care homes were often on quite ‘*complex regimes*’ which required medicines to be given at precise times. They highlighted delays in care continuity when this did not happen.

In contrast a nurse at Hospital B mentioned that although they checked what medications the person was taking on admission, they were not allowed to administer medicines brought in from care homes, so there was no expectation that care home nurses sent them.

5.2.4.2. At discharge

All hospital nurses discussed their role in organising medicines at discharge. Similar processes and extensive activities were described at both hospitals. The steps involved in ordering and checking medications were illustrated by one nurse,

> “***Well obviously the doctors prescribe, so the doctor will, will do whatever’s need prescribing, carry it on over, um, on the EPR (electronic patient record). The nurse will then do the check, make sure the patient’s either got it or contact the care home and ask them what medications they’ve got still there, explain any changes. They’ll then contact pharmacy that they’ve sent it through on the electronic system, and then they’ll wait and then when it comes back they’ll do all the checks to make sure it’s the right medication. And then obviously when the patient’s discharged, they, they ensure that medication goes with the patient”***

(P28, senior nurse, elderly care ward, Hospital A, individual interview).

A nurse from Hospital B provided a slight variation in the process, stating that it was pharmacy who normally contacted the care home about medication supplies.

All hospital nurses mentioned the process of organising medication was fraught with challenges. They mentioned how it could take several hours before the medicines arrived on the ward after they had been ordered. Additional delays were described such as those resulting from errors,

> "***Cause they (the doctor) don't always get that right, and that's what I'm saying, they might, you know, all the patients with hip, um, fractures have to have the tinzaparin injections for 35 days post-op, and they might forget to put that on."***

(P12, orthopaedic ward, Hospital B, individual interview).

Such errors would trigger contact with the prescriber or with the pharmacist depending on where the error had originated. Hospital nurses mentioned that these delays affected a timely discharge for the person living with dementia, as they may have to wait for several hours.

Nurses from both hospitals explained that owing to discharges being made quickly because of the need to create bed capacity, there was little opportunity to prepare take home medications in advance,

> ***"Maybe on the downstream wards (specialist wards) they've got a better chance of doing that (ordering medication in advance), but on here people can come in on the night shift and they'll be going home……within hours, really. Like we've got people, you know, what I'm sending back to care homes, so they would've only been on the ward literally hours or overnight…and I'm sending them back today"***

*(*P25, assessment ward, Hospital A, individual interview).

This was commonly reported by nurses working on the short stay wards. Nurses working on specialist wards mentioned having opportunities to organise medications a day in advance of discharge which meant medicines were readily available on the day of discharge and resulted in timely discharges.

Two senior nurses from one hospital mentioned that the current system of ordering medicines was not ideal. They suggested care home nurses obtaining prescribed medication from their community pharmacist may be more timely and would negate the person having to wait for the hospital pharmacy.

Several care home nurses from two care homes discussed liaising with the hospital pharmacist, prior to discharge. Pharmacists would contact them to ensure the care home had supplies of medication for when the person was discharged. This communication helped care home nurses to feel better prepared for the discharge,

> **“I find it really beneficial when the pharmacists have made contact with us. ‘Cause often there is a lot of medication changes. So, I think if the pharmacist gives you, um, you know, that phone call, you know, on the day when they’re coming and the changes are given to you, then it just makes you, you should know what to expect”**

(P23, Focus group,CH4).

5.2.3. After discharge

All care home nurses discussed activities relating to checking and organising medication when a person returned from hospital, similar processes were explained. Care home nurses reportedly checked the prescription and that the medication matched what the prescription stated. A nurse from one care home additionally described updating the prescription with any new or discontinued medication with their community pharmacist.

Despite the rigorous checks hospital nurses reportedly made, many care home nurses said they frequently experienced challenges with unclear information about prescriptions, insufficient supplies or missing medication. Care home nurses participating in a focus group discussed occasions when hospital supplied medication would only last a few days. This was particularly difficult if the person was discharged at the weekend. It meant care home nurses would need to contact the out of hours surgery to obtain a further prescription.

Nurses from three care homes discussed incidences of missing medication or information relating to prescriptions. Two nurses mentioned incidences when no information had been communicated about pain relieving medication including when the last dose had been administered,

> “***What they often don’t send is they won’t send a copy of the MAR chart. So, you know, they’ll come, people will come like I had a lady who came in yesterday who’s on paracetamol four times a day, and as soon as she got here she’s like, oh, I’ve got pain and I need them, but we didn’t know what time she’d last had it”***

(P18, team leader, CH1, individual interview).

*S*imilar issues relating to time sensitive medication such as treatment for Parkinson’s disease were also raised. Furthermore, a mental health nurse at one care home discussed how she had to make several phone calls to ascertain when a slow-release injection which was given monthly had last been administered. It was acknowledged such delays in obtaining information or medication impacted on the nurses’ ability to provide optimal care.

Summary of checking and organising medication

Most hospital and care home nurses describe relying on each other to ensure correct medicines were available when the person living with dementia was transferred to the care setting, be it at admission to or discharge from hospital. Yet insufficient information about prescriptions and inadequate supplies of medication were reported by both hospital and care home nurses. There was agreement on these issues from both hospital and care home nurses. Hospital nurses describe a challenging system of ordering medicines, with frequent delays occurring, which negatively impacts on a timely discharge for the person. Care home nurses spend time in clarifying prescriptions and obtaining supplies of medication.

This category was deemed to meet meaning saturation as checking and organising medications was a key role that was discussed by all participants. Although I consider more detail could have been obtained on this topic in relation to this role at admission to hospital. Only a few hospital nurses discussed this, those that did expressed strong emotions indicating it was seen as a significant issue in the transitional care process and therefore may warrant further exploration.

5.3. Chapter conclusion

In this chapter I have provided the detail of four nursing roles that hospital and care home nurses engage in when they provide care to people living with dementia who transfer back to their care home after a hospital stay. Nurses engage in the exchange of information, they assess and meet both the psychological and physical health needs of the person, they work with families of the person and check and organise the person’s medication. They described several nursing activities which make up these roles. These activities are conducted over the four phases of the transition pathway.

In describing their role, nurses identified several challenges in performing the nursing activities. In the next chapter, I will describe what facilitates the nurses’ role and I will present a synthesis of the findings of the hospital and care home nurse perspectives of their role in proving optimal care at this transition.

Chapter Six: Facilitators for optimising nursing care for people living with dementia when they return to their care home from hospital

6.1. Introduction

In this chapter I will present the answer to the second research question of the study

> *What are the facilitators for optimising nursing care for people living with dementia returning to their care home from hospital?*

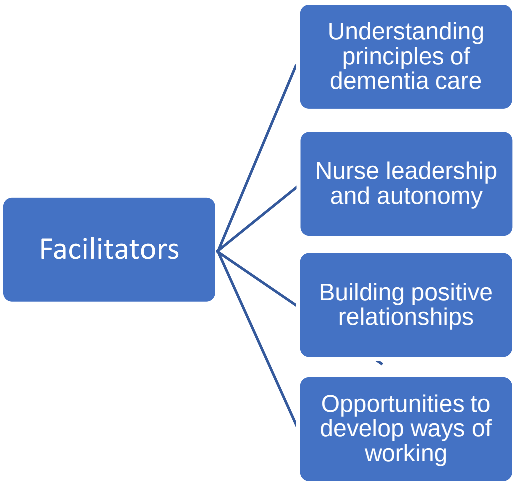
Four facilitators which optimise the provision of nursing care were identified:

1) Understanding the principles of dementia care,
2) Nurse leadership and autonomy,
3) A positive relationship between hospital and care home nurses,
4) Opportunities to develop ways of working.

I will use anonymous quotes, participant demographic data, my reflections from interviews and presentations to illustrate the findings. I conclude the chapter by synthesising the findings of the nurses' role and present four themes which emerged from the nurse's perceptions of performing their role. These are:

1. Interdependent/interdependence in roles,
2. Variation in how roles are performed,
3. The distinct needs of people living with dementia,
4. Care home nurse exclusion or not recognised as a member of the healthcare team.

6.2. Facilitators for optimising care



In this section I report on the four facilitatory mechanisms that were identified for optimising nursing care at this transition. These four themes were identified when nurses described their roles and discussed the nursing activities, they engaged in.

6.2.1. Understanding the principles of dementia care

Many hospital and care home nurses appeared to have a good knowledge of dementia care. Hospital and care home nurses mentioned a range of strategies they used to support people living with dementia with the challenges a transition can have for the individual. Many of these were presented in section 5.2. The demographic data presented in section 4.4.4.3 show thirty-two of the thirty-three nurses had undertaken dementia training. Among those interviewed, three hospital nurses were dementia champions who gave many illustrations of either how they supported people and described how this necessitates a flexible and individual approach. There was agreement from several hospital and care home nurses that knowing about dementia and about the person were key for optimising care at transitions. My reflexive field notes also indicated my impression was that most nurses had a good knowledge of dementia care.

“Other good examples of understanding the needs of care home residents living with dementia. I have been surprised that many of the hospital nurses demonstrate a good understanding of dementia care. My previous role of teaching post registration dementia care courses shaped my presumptions that they may not have a good understanding. Almost all the participants

have received dementia training and understand the principles of dementia with many giving good examples of how they respond to reduce distress" (Reflexive field notes after interviewing participant 33).

There were a few hospital and care home nurses who disclosed having personal experience of family members who have dementia or live in care homes. They considered that these experiences increased their levels of empathy for people living with dementia and their families,

> *"**And I think a lot of us as well as nurses we've been there with our relatives, you know, so our empathy and the way we deal with it you know, both my parents ended up with dementia"***

(P7 CH2, individual interview).

Additionally, several care home nurses from three care homes discussed staff and residents in the care home as being part of a family. They mentioned that several of the residents had lived in the care home for a few years, so they knew them well. One nurse considered that the '*homely environment* 'where she worked created a sense of '*home'* for the person. It was implied that strong bonds were formed with residents, which enabled care home nurses to get to know residents well and provide a personalised approach. One hospital nurse also remarked that there was sense of family between some care home staff and the care home residents.

I regarded this theme as having achieved meaning saturation because the majority of nurses participating in either an interview or group demonstrated a good level of dementia knowledge and provided examples where this knowledge contributed to an optimal transitional care experience.

6.2.2. Nurse leadership and autonomy

Some hospital nurses described having the power to influence and the illustrations they provided during discussion demonstrated they had a level of autonomy. For example, senior nurses at one hospital discussed working outside normal discharge procedures to prevent a person living with dementia having to wait for medicines, before being able to return to the care home. In this example, they organised transport to take the person back to

the care home before medication was prepared. They arranged for the medication to be sent later to the care home. A few nurses additionally mentioned presenting argument to managers regarding why it might not be appropriate to transfer a person even if their bed was required.
There were just three examples of nurses' autonomy shared by care home nurses from two care homes. Two nurses discussed they would be '*firm with the hospital'* and would not accept a person back from hospital if it were late in the evening. One nurse mentioned proactively advocating for a resident to be discharged early because of distress.

There was agreement from senior nurses at both hospital sites of the importance demonstrating leadership with their peers. For example, one discussed role modelling frequent communication with relatives and care home nurses. A second senior hospital nurse mentioned how they train junior staff to learn to effectively coordinate hospital discharge. A nurse from both sites each mentioned the importance of the ward manager or senior nurses '*being aware of all discharges'*. A third senior nurse discussed the importance of '*stepping in'* when required, to ensure discharge is effective.

> ***"Making sure that that's well managed, because I know I've had conversations this morning with a couple of junior staff around some complex discharges, didn't seem to be going anywhere as quickly as maybe they should, so I stepped in [..] and said, right, you know, you need to do this, this and this and gave them some guidance, and they've gone off to do what I said, you know, within some boundaries. But it's because they don't have the experience to think a little bit more broadly"***

(P16, senior nurse, intermediate care ward. Hospital A, individual interview).

Examples of nurse leadership and autonomy came from nurses who had over ten years of nursing experience and or were in leadership or senior role. My reflexive field notes recorded after the last interview conducted at Hospital A also illustrates this point.

"*An experienced nurse, demonstrating confidence and assertiveness, taking initiatives and giving another example of working outside of normal procedure. Being autonomous to get things done for the resident going back* *to the care home. Not afraid to speak up, good leadership, talks about the need for flexibility…"* (Reflexive field notes after interviewing P29).

I concluded this theme achieved meaning saturation particularly among the hospital nurses interviewed. This decision was not reached looking at the number of nurses who contributed to this theme but the examples given by the nurses who described in depth autonomous practice and demonstrated leadership. I considered these examples were significant in improving transitional care. There were fewer care home nurse perspectives relating to this theme, more details could have been obtained, and therefore further investigation in the context of care home nurses could be further valuable.

6.2.3. Building positive relationships between hospital and care home nurses

There was agreement from both hospital and care home nurses that they relied on each other to provide optimal care. Some hospital nurses recognised that this required developing relationships with each other. There were a few hospital nurses who mentioned there were care homes that they were more familiar with and where they knew the staff that worked there. They mentioned how communication was often better with nurses from these care homes and that they felt more able to share information. However, these discussions were with nurses working in the specialist wards at both locations. Notably a senior nurse from the short stay ward at Hospital A admitted they did not get opportunities to get to know care homes to the same extent.

At Hospital A, a senior nurse mentioned that there was a 'named nurse system' in place on the wards. She explained that the 'named nurse' is a registered nurse who is allocated a group of patients and is responsible for coordinating the patient's care. She explained the advantage was that the care homes and family knew who to contact in the hospital and that this helped to build relationships. She considered this was important,

> ***"you can have two and three patients on your ward at any one time from these homes and for me it's about trying to build relationships, not trying to create this 'us and them' "***

(P15, Senior nurse, dyadic interview, elderly care, Hospital A).

Although no nurses at Hospital B talked about this way of working, they did describe a ‘nurse to nurse’ handover sheet that gave the name of the nurse responsible for coordinating the discharge. I was told this was to inform care home nurses of who to liaise with both during and after discharge of the person back to the care home.

Several care home nurses from two care homes implied that relationships were at times adversarial with the hospital. This was identified during conversations about information exchange and medication at discharge. The descriptions of these activities were often discussed in context of strong emotion, where irritability and frustration were apparent. I identified this in my reflexive field notes.

“*I am getting the impression that relationships between care home nurses and hospital nurses can be tense and fraught. The consequences of poor information exchange at discharge seems to be a source of this tense relationship. I get the sense there is desire for relationships to improve. They discuss scope to work together and understand each other better”*(Reflexive field notes after individual interviews participants P9 and P10)

Although only a few nurses identified this as a facilitator for optimising care, I believe this theme was saturated. Several nurses implied poor relationships were a barrier to effective transitions and I considered this added weight to the conclusion that the opposite (good relationships) could contribute to optimising transitional care.

6.2.4. Opportunities to develop ways of working

Care home nurses from two care homes identified a need for opportunities for hospital and care home nurses to meet and discuss transitional care working practices. They considered these opportunities would contribute to improving communication between the two settings. A senior nurse of one care home mentioned she would like to see regular fora occurring for hospital and care home nurses to meet. This would facilitate them to gain understanding of each other’s roles and develop solutions to some of the common challenges they experience.

Care home nurses participating in a focus group also mentioned the need for a meeting with hospital nurses to agree a ***‘defined pathway about who does what’*** (Focus group, CH1).

One nurse suggested it would be beneficial for opportunities for hospital and care home nurses to exchange roles so they could gain insights into each other’s roles and care home environments,

> “***maybe it might be nice if nurses from the hospital side do come and look and spend some time in a care home. Because it can be like Emergency Ward 10 and it can be like a hospital, [ ] You know, yeah I think if they came into a, into care settings, you know, because we, we usually start out life as, you know, in the hospital, so we have more of an idea. But again, things have changed over the years, so I wouldn’t mind going and, you know, doing a week or so there just to see how things were and what happened and, and then we have got a, a better understanding”***

(P7, unit manager, CH2, individual interview).

These suggestions acknowledged a current lack of understanding about each other’s role and care setting.

Both hospital and care home nurses provided several suggestions about developing ways of working which would optimise care at transition. For example, hospital nurses mentioned standardising some processes for people transitioning between care settings, such as a consistent use of the ‘*red bag scheme’* for all care homes. A few hospital and care home nurses agreed that having a ‘*joined up electronic care record’* could improve information exchange. Hospital nurses considered care home nurses and community pharmacists having a more active role in providing medicines at discharge may solve some of the current challenges in organising medication at transition. Care home nurses also having a more active role in providing transport for the person living with dementia when they are discharged from hospital was suggested by both hospital and care home nurses.

These suggestions highlight nurses have many service improvement ideas, but there appeared to be lack of opportunity to express or propose these. It was considered creation of such opportunities could facilitate improvement in transitional care.

When presenting this finding at a national nursing conference, a member of the audience mentioned a hospital and care home initiative. She explained in their geographical area that senior hospital-based nurses were meeting with care home managers and senior care home nurses to discuss transitional care processes. She said it was a useful way to understand each other’s way of working. This adds to the perceptions of nurses in this study that such opportunities could help to develop optimal transitional care.

This theme did not achieve meaning saturation on the basis of numbers of nurses discussing it. I consider it saturated because I judged the ideas put forward by both hospital and care home nurses were important for improving transitional care. The resonance from audience discussion at conference presentations also contributed to this understanding.

6.3. Synthesis of findings

I will now summarise my interpretations of hospital and care home nurses’ perspectives on their role in providing optimal care for people living with dementia when they return to their care home after a hospital stay. Nurses described several activities which contributed to executing the four nursing roles: exchanging information, assessing and meeting needs, working with families and checking and organising medication. In describing their activities four themes were identified which were common to each of the nursing roles. These were 1) interdependent roles, 2) variation in how roles are performed, 3) distinct needs of people living with dementia, and 4) exclusion of care home nurses or not recognised as a member of the healthcare team. I now present a summary of the identified themes

6.3.1. Interdependent roles

Roles were interdependent. For example, effective assessment of and response to the person’s health and psychological needs was dependent on exchanging information. Hospital and care home nurses relied on each other to execute these roles well to ensure optimal care in transition from hospital back to care homes.

Many nurses agreed their expectations of each other were not met which made performing their own role challenging. For example, if care home nurses provided insufficient information about the care home resident at admission, it compromised the hospital nurses' ability to meet the specific needs of the individua. Nurses reported this was more challenging in the case of people living with dementia because they were more likely unable to communicate their own needs. These unfulfilled expectations led to frustration and adversarial relationships which in turn could affect hospital and care home nurse future collaboration.

At two conference presentations, one national and the other international, the interdependent relationship between hospital and care home nurses was referred to in audience discussion when I presented this finding, acknowledging role interdependence is common.

Nurses also described an interdependent role with residents' families. Hospital and care home nurses described relying on families for providing information and or support in helping them to assess and meet the person's needs.

I deemed this theme reached meaning saturation, as when I examined each of the categories I found examples where interdependence was described by several of those interviewed. The resonance with the finding at conference presentations and discussions with my research supervisor also contributed to making this judgement.

6.3.2. Variation in how roles are performed

Both hospital and care home nurses described a variety of ways they executed these roles. There was little standardisation or protocol driven care at transition. I will first highlight some examples of variation in hospital nurses' practice and then in care home nurse practice.

Hospital nurses

There was significant variation between hospital nurses in how they performed the activities. The particular type of hospital ward they worked in influenced how they performed their role, rather than the hospital they worked in. The most noticeable variation was between hospital nurses working in the specialist care wards and the nurses working on short stay wards. These nurses differed with respect to how much information they provided to care home nurses, the extent to which they engaged with care home nurses and at what point in the transition pathway this engagement took place. Hospital nurses perceived the rapid patient turnover in short stay wards contributed to the challenges in knowing and understanding the specific needs of the person living with dementia. As this was viewed as a facilitator for optimising care, it was more difficult for nurses from short stay wards to provide optimal care for people living with dementia. Care home nurses also commented that the extent of involvement they had in discharge and the information they received from hospital at the person's discharge varied. This might correlate to the type of ward the care home resident was discharged from.

Nurses in senior roles and those nurses with many years of experience also executed their roles differently to junior staff. They were more likely to deviate from procedure and use their influence to adapt the care for people living with people with dementia when this was required.

My reflexive field notes identified the differences in care between the short-stay and the specialist wards after the interviews at the elderly care ward at Hospital A and then again after interviews at the intermediate care ward at Hospital B. Here is an example of my notes.

"*It does seem that that nurses from this ward, execute discharges differently to that of the assessment ward and MAU. They seem to involve families more in planning and appear to know care home staff and liaise more frequently. They also aim to discharge the person earlier in the day even if it means putting it off for a day. They have a strong ward sister who seems to advocate a lot for plwd"* (Reflexive field notes following individual interviews with P28, and P29, elderly care ward, Hospital A)

<u>Care home nurses</u>

Hospital nurses reported widespread variation in care home nurses' practice. It was perceived that people living with dementia were often admitted to hospital without adequate information from the care home. Across three of the care homes there was no standard way in which care home nurses provided information about the person, each care home had their own systems for communicating information. Two care homes routinely provided care staff to accompany residents to hospital. This was to provide supportive care to the person and assist with information exchange. Hospital nurses valued this but indicated this practice varied by care home. There were inconsistent policies across care homes about timing of readmissions. This meant that those care home nurses working at homes with such policies could influence the timing of the transition which was considered particularly important for people living with dementia.

The variation in how nurses performed their roles meant that care delivery differed, and inconsistencies in care were reported.

At a presentation to one of the stakeholder panels, a carer had also faced inconsistencies in hospital discharge experience relating to the care of her relative who was living with dementia. On listening to my findings, she considered that the better discharge experience had occurred when her relative had stayed on an intermediate care ward, where the nurses had spent time understanding her relative's specific needs and had involved her more in the discharge planning. This added to my interpretation about variation across short-stay and specialist care wards. I consider this was a significant finding and therefore judged this theme had achieved data saturation.

6.3.3. Distinct needs of people living with dementia.

Hospital and care home nurses agreed that people living with dementia had distinct needs which required a different response to that of older people generally during this transition. They noted that an admission to hospital could have a negative impact on the person with dementia and they engaged in strategies to minimise distress. For those people in more advanced stages of dementia, nurses assessed levels of understanding and tailored care accordingly. The day of discharge was particularly challenging because of the pending further change in environment, the day was described as busy and discharge tasks such as arranging medication and transport could be uncoordinated. This could affect a timely discharge and nurses considered that early transfers were better for people living with dementia. Traditional forms of hospital transport and the planned journey back to the care home were considered inappropriate for people living with dementia and nurses sought to find alternatives.

Hospital and care home nurses sometimes provided examples relating to the care of older people in general in care homes, not specific to people living with dementia. These examples were associated with responding to physical health care needs. For example, discussions about catheter and wound care. These examples were included in the analysis as nurses identified they could apply to a person living with dementia if they were also living with that physical health condition. It highlights the complex care needs of people living with dementia in care homes.

At three conference presentations and at a clinical network event there was general consensus with the audiences that although hospital to care home transitions were often challenging for all care home residents there was recognition that people living with dementia had distinct needs that contributed to making this more difficult. The complexity of care needs that all nurses discussed added to my conclusion that this theme achieved meaning saturation.

6.3.4. Care home nurse exclusion or not recognised as a member of the healthcare team

Even though care home nurses were health care providers they were not viewed by members of the acute care system as a full member of their team. Most care home nurses reported having restricted access to information about their resident's health, well-being and functioning whilst they were in hospital. Yet hospital nurses expected care home nurses to share information about the care home resident. Care home nurses proactively provided this or did so when responding to requests. Disparity was noted between hospital and care home nurses' access to working with allied health care professionals. Some hospital nurses referred to and worked closely with the hospital allied health professionals, but care home nurses had to make referrals to community allied health professionals via the resident's GP if they wished to access after care for their resident. Additionally, care home nurses did not have access to shared electronic patient records which were accessible to some other members of the community-based health care team. Some hospital nurses agreed that the policies restricting care home nurses' access to hospital-based records of their care home residents was problematic. There was also disparity in handovers of care between hospital nurse to care home nurse and hospital nurse to hospital and primary care nurses. A few hospital nurses admitted their handovers to other hospital nurses or primary care nurses were more thorough. This implied hospital nurses do not view care home nurses as a member of the same healthcare system.

My reflexive field notes after undertaking individual interviews at CH1 identifies this.

"*Again, I keep hearing about this issue that care home nurses do not have access to information about their care home resident whilst in hospital. They also feel excluded from the discharge Why aren't they more included as part of the wider team?"* (Reflexive field notes after individual interviews P17 and P18).

I considered this to be a significant issue in the story of transitional care between hospitals and care homes for care home residents living with dementia. I judged this theme to reach meaning saturation, as I repeatedly heard care home nurses were excluded particularly in the care home nurse sample, but this may warrant further exploration with hospital nurses.

6.4. Chapter conclusion

In this chapter I presented both hospital and care home nurses perceptions of what optimises care for people living with dementia when they return to their care home after a hospital stay. Four facilitators were identified which optimised care at this transition which were: nurses understanding the principles of dementia care, nurse leadership and autonomy, building positive relationships between hospital and care home nurses, and opportunities for hospital and care home nurses to develop ways of working.

In performing the nursing activities of the four roles presented in chapter five, it was found that nurses had interdependent roles, there was variation in how they performed their roles and care home nurses were often excluded from transitional care processes and not recognised fully a member of the healthcare team. Additionally, people living with dementia had distinct needs to that of older people generally which required nurses to provide a different response.

In the next chapter I will report on how the nursing activities described by hospital and care home nurses align to best practice guidance.

Chapter seven: Mapping nurse’s roles to cited best practice

7.1. Introduction.

In this chapter I present the findings to my third research question.

3. *Does the care provided by hospital and care home nurses, align to best practice guidance, the components of effective transitional care, as identified by Naylor et al. (2017)?*

I present the results of the deductive dominant qualitative analysis. This involved aligning the nursing activities which make up the four nursing roles identified in the inductive content analysis, to the strategies suggested by Naylor et al. (2017). These strategies were created to achieve each component of care in the model of care they developed. The strategies were identified from published evidence. The original development of these care components applied to hospital to own home transitions. I have made some slight adaptations to the strategies and one care component to account for the hospital to care home transition.

First, I give the definition for each component of care that Naylor et al. (2017) provided in this model of care and the suggested strategies for achieving it. I then present a table of the nursing activities aligned to each strategy with some illustrative participant quotes. I conclude the description of each component of care with a summary of my interpretation of the degree in which the nurses’ activities addressed the component.

Naylor et al. (2017: 2) defines a transitional care component as,

> “***a critical element of traditional medical care, community-based services, and non-traditional services provided by the health care team that patients and caregivers should receive to promote positive health outcomes throughout periods of acute illnesses extending from hospital to home.”***

In their study they identified eight components of comprehensive and effective transitional care:

- Complexity management

- Care continuity
- Patient and caregiver well-being
- Accountability
- Family caregiver engagement
- Patient engagement
- Patient education
- Caregiver education (Naylor et. al. 2017: 4).

They concluded that the degree of attention given to each component varies depending on the specific needs of the patients and carers. However, they stress that all components should be addressed by healthcare systems during transitional care to deliver best practice. They recognised although they have defined each component separately, they are inter-related and should be viewed as a holistic care process (Naylor et al., 2017: 3).

7.2. Complexity Management.

Naylor et al. (2017: 3) highlight that people living with chronic illnesses present with numerous challenges of care which include managing complex physical, social and emotional needs. They emphasise that managing complexity is achieving holistic person-centred care characterised by anticipation, prevention or early identification of problems. Medication management is also an important function to ensure optimum therapeutic outcomes and a reduction of adverse events (Naylor et al., 2017: 3). The authors identified ten strategies from published evidence (Naylor et al., 2017: 5),

1. Identifying high risk patients
2. Anticipating and planning for common transitional care problems
3. Managing co-existing chronic conditions and other health and social risks
4. Preventing the occurrences of posthospital syndrome (a period of vulnerability following hospital discharge)
5. Aligning health and community services with patients and carers goals
6. Ensuring the medication management plan is based on evidence
7. Respecting patient’s choice in adherence to plan
8. Providing appropriate information and training so that the patient is

knowledgeable and confident
9. Evaluating access to medications
10. Monitoring to avoid medication errors.

In my study hospital and care home nurses discussed the complexity of care home residents' needs and how they addressed them. Table sixteen illustrates the alignment of nursing activities to Naylor et al.'s (2017) suggested strategies.

Table Sixteen: Care component, Complexity management

Definition: Managing complex physical, social and emotional needs		
Naylor et al.'s (2017) strategies	**Nursing activity**	**Illustrative quotes from hospital and care home nurses**
Identifying high risk patients	Meeting psychological needs	*So if they're say, um, not very mobile and they can't sit in a chair, then it might be a stretcher is the safest, and especially some patients are agitated at times. Um, it's not safe to go in a chair where potentially they might get up (P12, H nurse, individual interview).*
	Assessing for discharge	*The main risks are, I mean… well the changes, if they, they have the changes in their abilities and they are having a swallowing difficulties [ ] I mean, if they have major changes in there, we have to reassess them (P19, CH nurse, individual interview).*
Planning for common transitional care problems	Meeting psychological needs	*We try to orientate people and... We would always recommend that people are discharged quite early in the day because I know that people are more unsettled on the evening it's just really distressing for the (P26, H nurse, individual interview).*
	Assessing for discharge	*If they've got infections which are impacting on their, their behaviours anyway. At least if we know, this person is quite heightened at this time, if they found it a distressing experience, at least we can prepare and discuss, okay, do we need to put an extra person to spend some extra time with them until they've settled back home (P21, CH nurse. Focus group).*
Managing co-existing chronic conditions and other health and social risks	Assessing for discharge	*Simply because of the, um, you know, the complexity of the discharges, the vulnerability of the people that you're discharging, so everything's pre planned and you can't just suddenly say to a 100-year old or a 90-year old person, right, you're out in an hour's time. So, if you add into that a cognitive problem, you need to be preparing people (P16, H nurse, individual interview).*
	Assessing on return	*We assess their physical well-being in general and see how they are,[ ] their psychological needs are immediately addressed as well, people can arrive back confused, disorientated, especially someone with dementia, they might have thought they were going home and not actually remember they live here, yes, so that can be quite distressing, it's like being readmitted all over again. It's good to make sure there are staff around to if they know them quite well to go in and re-orientate them really (P9, CH nurse, individual interview).*

Preventing the occurrences of posthospital syndrome	No activities aligned	
Aligning health and community services with patients and carers goals	No activities aligned	
Medication management – ensuring medication plan based on evidence	Checking and organising medication at discharge	*Fractures have to have the tinzaparin injections for 35 days post-op, So it's when it (medications) comes back and we pick up on that, it's like we say don't they need tinzaparin? (P12, H nurse, individual interview).*
	Checking and organising medication on return	*I had to contact the ward, where he came from, and then they just told me on the phone, I was to use the same dressing for all the wound, that was the message I received from the nurse, but it (the wound) was really bad, finally I got the tissue viability nurse, she came to reassess the wound and all the dressings were changed (P4, CH nurse, dyadic interview).*
Respecting patient's choice in adherence to plan	No activities aligned	
Providing appropriate information and training so that the patient is knowledgeable and confident	No activities aligned	
Medicines management – evaluating access to medication	Checking and organising medication at admission	*I'm afraid I, they (care home nurse) get a lecture sometimes. Why have you not sent them (medications) to hospital, we don't have everything here, they're on Parkinson's treatment, some of them every two hours, quite complex regimes, we need that medication (P15, H nurse, dyadic interview).*

	Checking and organising medication at discharge	*It is usually the pharmacists who rings and says have you got enough medications there because there is not much changes in this person's medication. I say we do have enough supply here of the medications, but if there are changes they send us the supply if we don't have that,* *(P1, CH nurse, Focus group).*
Medication management – monitoring to avoid errors	Checking and organising medication at discharge	*Pharmacy says, oh, yeah, we've checked, it's okay, the doctor's done the prescription, all okay, and then suddenly when you're checking at the end of your process, and you [ ] just check it against the drug chart and against your medication and, oops, oh, no, this is not right. So you have to go back to the doctor, delete or add whatever needs doing…and then get back to pharmacy so they have to redo it again (P24, H nurse, individual interview).*
	Checking and organising medication on return	*Cause maybe some of the medication was changed. Or does not come with the, right or full medication, just a few of them despite on the discharging letter it says they're providing a new supply for 14 days or for 28 days, you don't find them, you have to sometimes we need to ring back. Hello, is this the right medication? you did not send this, or you did not send the other (P17, CH nurse, individual interview).*

Four out of the ten strategies for complexity management suggested by Naylor et al. (2017) were not described by either hospital or care homes nurses. Three of these strategies were connected to patient engagement activities. The person living with dementia appeared to have a passive role in their care. Overall, both hospital and care home nurses described nursing activities which aligned well to addressing this care component of complexity management.

7.3. Care continuity

Naylor et al. (2017) define care continuity as comprising three domains,

1. Management continuity encompasses comprehensive implementation of individualised care plans and timely access to health and community services
2. Information continuity refers to the timely exchange of information between all team members
3. Relational continuity includes the access to continuous sources of care to foster trust with patients and caregivers (Naylor et al., 2017: 4).

Naylor et al. (2017) suggested three strategies to achieve the care component (Naylor et al., 2017: 5),

1. Ensuring follow-up with primary care clinicians, home care or community-based services
2. Communicating effectively among inpatient team and community-based healthcare team
3. Encouraging members of the healthcare team to engage patients and carers in trusting, reciprocal, respectful relationships.

During my research, the majority of nurses working in hospital and care homes discussed activities which contributed to providing continuity of care. Table seventeen illustrates the alignment of nursing activities to Naylor et al.'s (2017) suggested strategies.

Table Seventeen : Care component, Care continuity

Definition: Three domains, Informational, Relational and Management Continuity		
Naylor et al.'s (2017) strategies	**Nursing activity**	**Illustrative quotes from hospital and care home nurses**
Ensuring follow-up with primary care clinicians, home care or community-based services	Assess for discharge	*So, you've got to make sure several things come together all at the same time, I think you've got a responsibility to make sure that happens. So this lady's waiting for a piece of equipment going in (to care home) which maybe could have gone in today but they can't guarantee that's it's going to go in, and I can't send her back because I don't think she's safe to go without it. I think you've got to just sometimes not only look at the fact that we are really pressured for beds, but it's got to be done safely, hasn't it? (P26, H nurse, individual interview).* *And they (the hospital nurse) usually contact us, um, and we can, we are invited to go out (to carry out assessment) if there's a vast change, and we will speak over the phone about, you know, what changes and any equipment that they might need. Obviously, this is a nursing unit, we do supply, you know, mattresses, profile beds and all that type of thing that we would need (P7, CH nurse, individual interview).*
	Meeting physical health needs	*Yes, let's say they wanted to be seen by the neurologist, but they did not manage within the period (of hospital admission) they put it for you to like follow up, like contact them and arrange an appointment with them, so I will do that (P17, CH nurse, individual interview).*
	Checking and organising medication on return to care home	*And even making sure that, you know, whatever changes happen with their medications, getting a doctor back in, you know, from surgery and review and see whether they need all those medications and make sure things are available (P6, CH nurse, individual interview).*
Communicating effectively among inpatient team and community-based healthcare team	Providing information	*Yeah. They will always ring us back for [ ] sometimes if they need to get a little bit of background of, how they are, and what about the baseline. So we always get calls from the doctors, nurses, or sometimes the physio, say, regarding the mobility* (P19, CH nurse, individual interview). *It's all communicated beforehand verbally to the care home but it's there in the document form as well, and make sure enough equipment goes back like catheter bags and dressings and things like that go with them (P33, H nurse, individual interview).*

	Receiving information	*We've only had a couple of patients though through with the red bag and I have found it quite helpful, the, the residents that did come in did come with absolutely everything, so all their notes, told us everything they liked, what they didn't like, even the care home manager came in and started filling some bits in that they, knew that had happened. And they did come in with all the medicines, change of clothes, pyjamas, everything (P14, H nurse, dyadic interview).*
	Seeking and clarifying information	*It's about engaging that care home, saying actually, um, this patient might need a bit of rehab, it might be that they need assistance of two, there might be a hoist. Um, so have they got that equipment, do they need that equipment getting in? So then it's about liaising with them on that aspect, making sure that that equipment is there (P12, H nurse).* *Usually I do call on a day-by-day basis. For me usually, if they're in hospital because I strategically call in the afternoon after the consultation round… and hopefully they give us an update (on resident's progress) (P22, CH nurse, Focus group).*
Encouraging members of the healthcare team to engage patients and carers in trusting, reciprocal, respectful relationships	Conducting nursing assessment at and during hospital admission	*So, we pull all the staff in, have… well we're constantly engaging with like the,the care home, even relatives and the ward staff, the therapy staff and trying to make out, make sure that we're covering all aspects and making sure that everything's in place to get them patients back (P13, Hospital nurse, individual interview).*
	Liaising with family to provide information and support	*And what happens when, when someone goes to hospital is we always send a member of staff with them, but obviously we get in touch with the family and so the member of staff will stay until the family member gets there (P18, CH nurse, individual interview).*

Several nurses from both hospital and care homes described activities that aligned well to all three of the suggested strategies, although I acknowledge that several nurses in both hospitals and care homes also discussed examples when care was lacking in this area. This suggests that hospital and care home nurse engagement is essential in achieving care continuity.

7.4. Patient and caregiver well-being

This component of care is about the recognition that patients and carers can experience emotional reactions when faced with stressful situations such as discharge. Naylor et al.’s, (2017: 2) paper defines a caregiver as “family members, partners, friends or neighbours who provide unpaid support”. The term ‘caregiver’ is generally an unfamiliar word in the UK, often the word ‘carer’ is used. The nurses who were interviewed, used the term ‘family’ to describe caregivers as per the above definition. I have therefore replaced the word ‘caregiver’ with ‘family carer’.

In defining this care component Naylor et al. (2017) stated that the healthcare team should respond to these emotional reactions by fostering coping skills, treating people as whole human beings and with respect and be supportive of decisions that contribute to quality of life. They suggest three strategies which can contribute to addressing this component (Naylor et al., 2017: 5)

1. Fostering early identification and interventions to address emotional distress
2. Recognising family carers common concerns regarding reactions to family carer’s role, including fear of harming their loved one
3. Identifying and implementing effective strategies to support patient and family carer’s emotional well-being.

Table eighteen illustrates the alignment of nursing activities to Naylor et al.’s (2017) suggested strategies.

Table Eighteen: Care component, Patient and family carer well-being

Definition: Recognition that patients and caregivers can experience emotional reactions when faced with stressful situations which require a response from the health care team		
Naylor et al.'s (2017) strategies	**Nursing activity**	**Illustrative quotes from hospital and care home nurses**
Fostering early identification and interventions to address emotional distress	Meeting psychological needs	*Yeah and for us it's about trying to facilitate a more early discharge if you possibly can, because we feel the longer they're in, moved from ward to ward, it causes more problems really. And if it's something simple, um, that you know, we feel they can cope with (P15, H nurse, dyadic interview).* *There needs to be a focus on their psychological care, made sure it's done calmly and properly and they are kept well informed, and not quick but you know what I mean, door to door transport at least. That sort of thing. Considering how they are and what affect that transfer is going to have on them if it's not done smoothly really (P9, CH nurse, individual interview).*
	Liaising with families to provide information and give emotional support	*Trying to engage that patient as much as possible, um, and the relatives, and making sure that we are making sure things are in place and that they are happy with it, that transition for that patient is gonna be as smoothly as possible (P12,H nurse, individual interview).* *It can be stressful for the family[ ], I mean the other day we've got a gentleman who's in hospital at the moment [ ]and his family came in on Tuesday to see me and have a chat about how he's getting on and really wanting to be reassured that on discharge he'll be able to come back here and things (P18, CH nurse, individual interview).*
Recognising family carers common concerns regarding reactions to family carer's role, including fear of harming their loved one	No nursing activities aligned	

Identifying and implementing effective strategies to support patient and family carer emotional well-being	Involving families in providing supportive care to the person	*Providing familiarity, can family members be there or go with them so when they arrive (back at the care home) they've got that connection, that friendly face (P33, H nurse, individual interview).* *If they are fit for discharge, it's much better for the resident if they were brought back by a relative, or, so it's a reasonable time of day so they are not sat around waiting for hours for transport or going round different houses (P9, CH nurse, individual interview).*
	Meeting psychological needs	*So we do spend time with them. Because it, it is difficult, you know, because they are unaware of where they are, they're disorientated to time, place, person, etc. So, you know, we do spend time with them (P7, CH nurse, individual interview).* *You just have to remember that certain ladies or men with dementia have things that they really like around them, so it's (not) really good to pack all the stuff up and pack that favourite whatever it might be, whether it's a favourite teddy bear some ladies have, the men might just have, just might be a photograph on the table, and we're very good at just packing everything in the bag because that's what we need to do, because we need to pack for the ambulance. I think just, just considering that they've got dementia. They don't actually know what's going on so we need to try and just make it as stress-free as possible (P27, H nurse, individual interview).*

The majority of hospital and care home nurses described nursing activities that aligned to two of the three strategies in achieving patient and family well-being. They described activities to achieve the person's well-being. Discussions about addressing family well-being were less prominent in the interviews and. Recognising family carers common concerns regarding the family carer's role, including fear of harming their loved one did not feature in any of the nurse interviews.

7.5. Accountability

Accountability is defined by Naylor et al. (2017: 4) as “assuming responsibility for implementing high quality individualised transitional care services which are customised to meet the needs of patients and caregivers”. This component is spilt into three domains: clinician, team, and organisational accountability. Clinician accountability is defined as professionals and patients working in partnership to develop and implement plans of care. Team accountability acknowledges the need for collaboration and for each team member to contribute their expertise. Organisational accountability refers to the responsibility of the system to ensure the environment and services are conducive for optimal transitional care experiences (Naylor et al., 2017: 4).

Three strategies which could help to achieve this care component are proposed (Naylor et al., 2017: 5),

1. Fulfilling each clinician’s responsibility in a comprehensive timely manner
2. Collaborating as a team to ensure that patient and family goals and preferences are met
3. Providing reliable improvement support for transitional care programmes.

Hospital and care home nurses described activities that they considered to be their responsibility. Table nineteen illustrates the alignment of nursing activities to Naylor et al.’s (2017) suggested strategies. I also identified a new strategy for the hospital to care home transition: collaboration between hospital and care home nurse to agree the handover of duty of care.

Table Nineteen: Care component, Accountability

Definition: Assuming responsibility for implementing high quality individualised transitional care services via clinician, team, and organisational accountability		
Naylor et al.'s (2017) strategies	**Nursing activity**	**Illustrative quotes from hospital and care home nurses**
Fulfilling each clinician's responsibility in a comprehensive timely manner	Assessing for discharge and Providing information	*Our responsibility is mainly to make sure that they got everything with them. Definitely the medication, the discharge summaries are really important because you try to put yourselves into accepting nurse; when there's no documentation it's really hard to say, yeah. I think our responsibility is to make sure that they are safe to go with the correct, erm, the zimmer frame, you know, everything that they needed or their, property, whatever is, that they needed to go home with them. And to make sure that you've got give a, a full handover (P32, Hospital nurse, individual interview).* *I mean, that's what I mean if, when you… when they ring you and say this person's coming back, and rather than saying, oh that's fine…I have my duty of care to ask what has happened in the hospital or……er, when they're coming to, coming back to us the same way. I think I, it's my responsibility it's my duty of care,(P19, CH nurse, individual interview).*
	Liaising with families to provide information and give emotional support	*Yeah. So, you have, the nurse's responsibility is mostly everything really planning of the discharge, transport. So, if there are delays, you have to tell the relatives, you need to ring them and let them know there is a delay. Relatives will be wondering, should I go to the home, should I go to the hospital? So, you need to, you are responsible to let the family know that they are still there waiting, what they're waiting for, and the, and the home as well (P24, H nurse, individual interview).*

Collaborating as a team to ensure that patient and family goals and preferences are met	Assessing for discharge	*I think everyone should be responsible anyone who is involved in it really[ ] from hospital point view it's difficult for me to say but we are responsible for admitting people into hospital to make sure that goes smoothly and giving all that information, and to make sure it's safe for them as well, if the hospital rang up and said we are about to put someone in an ambulance at 6 o'clock on a Friday I would refuse to take them back because it is inappropriate for the resident, when they could come comfortably the next morning in daylight, those sorts of things (P9, CH nurse, individual interview).* *Erm, physios are obviously accountable for their own practice, aren't they? But as a nurse we're accountable overall aren't we, for that patient? [ ] we're accountable to make sure that that patient's been discharged safely. So, I that means that that lady needs a stairs assessment before she goes home, it's up to us to make sure that the physio's done that (P27, H nurse, individual interview).*
	Providing information and Seeking and clarifying information	*Um, and we always try, when people are discharged, if somebody rings up with an issue we always try to sort it out, um, ourselves. We don't just say, oh well you'll have to go to your GP or, you know, you'll have to do this or that. We always try and sort it out ourselves for them and do the ringing round because it's, like, the responsibility's ours. It's us that's not done that. I want people to remember (name of ward) as being a, a good place to be in that we can be trusted to look after their relative (P16, H nurse, individual interview).* *I think we are all (accountable) both sides really. I mean obviously if I'm sending somebody I like to be very thorough getting all the information together to send [..] and if I don't get everything that I'm hoping I'm going to get back from the hospital, I'll be on them, you know, I'll ring up and find out, you know, whatever's missing that we get it so we can provide that care for them (P7, CH nurse, individual interview).*
Providing reliable improvement support for transitional care programmes	No nursing activities aligned	
A new strategy identified for hospital to care home transition:	Providing information	*So as long as everything has been handed over, then that (accountability) then becomes the care home's, the continuing of care from us to them continues, and there has to be at some point a change over, otherwise we'd be accountable to everyone forever (P33, H nurse, individual interview).*

Collaboration between hospital and care home nurse to agree the handover of duty of care	Meeting psychological needs	*P21: when they (the resident) set their foot back here then we take over that accountability* *P20: In the same way, I think, when we take our residents to the hospitals, the moment that they're admitted it's, that's where our duty of care has to take a step back, 'cause somebody else has taken accountability of her (CH4, nurses focus group).*

Hospital and care home nurses' responsibilities as identified through the interview data were aligned with clinician and team accountability as defined by Naylor et al., (2017). Several nursing activities aligned with two of the three suggested strategies. During interviews, there was little discussion regarding organisational accountability about system responsibility, and no activities were aligned with the suggested strategy for providing improvement support and therefore this requires further exploration. These care components are designed for healthcare systems and not specifically for individual professionals and therefore not all aspects of the care components identified by Naylor et al. (2017) may apply to nursing activities.

The duty of care across settings was discussed by hospital and care home nurses. Handing over a duty of care was often implied rather than being an explicit process. This topic is not acknowledged in Naylor et al.'s, (2017) guidance as it was designed for hospital to home transitions. I added a suggested strategy to this care component to account for this missing element.

7.6. Family carer engagement

Naylor et al. (2017) purport that engaging with family carers is central and should be demonstrated by healthcare professionals identifying what outcomes of care are most salient to the family carer role. Health care professionals should assess the family's needs and capabilities, foster shared decision making related to plans of care, promote shared accountability for actions relating to care plans and ensure respectful and reciprocal relationships (Naylor et al., 2017: 3).

Five strategies to address this care component are suggested (Naylor et al., 2017: 5),

1. Conducting comprehensive assessments to identify family carers and determine their preferences and capabilities
2. Demonstrating respect for family carers as partners in developing care plans reflective of their goals
3. Monitoring family carers progress at achieving their goals and helping patients to meet their needs
4. Enabling timely bi-directional communication and care continuity
5. Continually evaluating family carers levels of engagement.

Hospital and care home nurses described activities in how they engage family carers and recognised families play an important role in the care of the person living with dementia when they are admitted into hospital. Table twenty illustrates the alignment of nursing activities to Naylor et al.'s, (2017) suggested strategies.

Table Twenty: Care component, Family carer engagement

<table>
<tr><td colspan="3">Definition: Identifying what outcomes of care are most important for their role in caring for their relative, assessing their needs and capabilities, fostering shared decision making, promoting shared accountability for actions and ensuring respectful and reciprocal relationships.</td></tr>
<tr><th>Naylor et al.’s (2017) strategies</th><th>Nursing activity</th><th>Illustrative quotes from hospital and care home nurses</th></tr>
<tr><td>Conducting comprehensive assessments to identify family carers and determine their preferences and capabilities</td><td>Nursing assessment at admission and
Liaise with families to obtain information</td><td><i>Obviously when they first get here we need a discussion with family and care home because, quite often families’ take on patient is different to a nursing home staff take on a patient [ ] also it depends what kind of feel you get for the whole situation as to what’s going on, but we get both perspectives (P16, H nurse, individual interview).</i></td></tr>
<tr><td>Demonstrating respect for family carers as partners in developing care plans</td><td>Liaise with families in care decisions</td><td><i>Families are always involved and the consultants on here are always involved with families in as much as the pathway through, you know, sort of a meeting with the consultant, we will arrange. So, there’s always communication, um, yeah, and especially with regards to discharge planning you know, we’d never do without sort of family involvement (P28, H nurse, individual interview).</i>
<i>Yeah, that’s a reason why (residents are admitted to hospital) the family Want it, ‘cause they see a treatment (intravenous) - no, I think ‘cause they see the affect after the antibiotic course better than, let’s say somebody who’ is going to take the medication will spit the antibiotic. Of course, the family think, ah, it is better if there (in hospital). I want my Mum or my Dad to go there (hospital) But mostly we try to avoid, if it’s treatable here</i> (P17, CH nurse, individual interview).</td></tr>
<tr><td>Monitoring family carers progress at achieving their goals and helping patients to meet their needs</td><td>Involve families in supportive care</td><td><i>It depends on the involvement of the family whilst their here, really I suppose is the answer to that, if you’ve got quite good involvement with the family and their quite involved, then it’s the next step isn’t it, you know, they’re going home on Thursday, you know, do you want us to book transport or do you want to take them, is that better… and it’s part of the discussion isn’t it (P33 H nurse, individual interview).</i></td></tr>
</table>

Enabling timely bi-directional communication and care continuity	Liaise with families to provide information and support and Liaise with families to obtain information	*We would inform families if someone was being admitted to hospital, and quite frequently the family members are down at the hospital to meet them you know, shortly after they've arrived* (P21, CH Nurse, Focus group). *So, yeah, I'd ring the care home, give them an update, ring the family, give them an update. And obviously when we find out they're going home, then the next step, I'd ring the care home and the relatives…and make sure they're happy (P25, H nurse, individual interview) .*
Continually evaluating family carers levels of engagement.	Liaise with families in care decisions	*You've gotta weigh up the fact of the client or the patient is in a, is in a nursing home setting, so they've obviously got nursing needs…and quite possibly dependence. So really, what you don't want to add is stress to the family of trying to get mum, dad, back to the care home, (P28, H nurse, individual interview).*

Nursing activities were described that met all five strategies. However, hospital nurses described more activities which aligned with the suggested strategies by Naylor et al. (2017) than care home nurses. Very few illustrative examples aligned to strategies such as comprehensive assessment of family's own needs and capabilities and continually monitoring family carer's level of engagement, suggesting less engagement with families in these areas. This suggests these areas require further exploration.

7.7. Patient Engagement

Naylor et al. (2017: 3) state patient engagement involves optimising the central role of patients in actively involving them in negotiating their goals of care. This involves assessing their perspectives, needs and capabilities, fostering shared decision-making related to care planning, promoting shared accountability for care plans and ensuring reciprocal and respectful relationships.

The following five strategies for achieving this this care component are proposed (Naylor et al., 2017: 5),

1. Conducting comprehensive assessments to identify patient goals
2. Demonstrating respect for patients as partners in developing care plans reflective of their goals
3. Monitoring patient progress at achieving their goals
4. Enabling timely bi-directional communication and care continuity
5. Continually evaluating patient's level of engagement

Table twenty-one illustrates the alignment of nursing activities to Naylor et al.'s, (2017) suggested strategies. I identified a new strategy to account for the specific needs of people living with dementia who may lack mental capacity: Identify appropriate proxy to act in the patient's best interests.

Table Twenty-one: Care component, Patient engagement

Definition Optimising the central role of patients in actively involving them in negotiating their goals and outcomes of care, assessing their needs and capabilities, fostering shared decision making, promoting shared accountability for care plans and ensuring respectful and reciprocal relationships.		
Naylor et al.'s (2017) strategies	**Nursing activity**	**Illustrative quotes from hospital and care home nurses**
Conducting comprehensive assessments to identify patient goals	Nursing assessment at admission, and on return to care home	*It is very much about getting background, um, and getting a baseline you know, it's no good trying to achieve something that, you know, the patient's not been able to do for many years or whatever. We directly ring the care home themselves, we might talk to the relatives, social workers, anybody that's directly involved (P16, H nurse, individual interview).* *Because what I would be doing would be actually looking at the resident when they're coming back and reassessing them anyway. So what, knowing what they were like before they went and what they are like now and what do we need to do if there's any other changes really (P8 CH nurse, individual interview).*
	Nursing assessment at discharge	*Well obviously sort of taking the patient into consideration themselves and not doing this all above them but involving them in it all the way down the line…and depending the level of severity of how it affects them, how they're able to function, depends on how we involve them in that discharge (P28, H nurse, individual interview).*
Demonstrating respect for patients as partners in developing care plans	No activities aligned	
Monitoring patient progress at achieving their goals.	Nursing assessment at admission	*So the patient might not be as mobile as they were before, so we need to clarify, um, how mobile they need to be how much longer they need to work with the physios and the OTs. and it depends on the patient and, all the nursing homes work really differently (P13, H nurse, individual interview).*

Enabling timely bi-directional communication and care continuity	No activities aligned	
Continually evaluating patient levels of engagement.	Meeting psychological needs	I *think just explaining to them, trying to sit down with them and, if you can, because some people with dementia obviously do understand. It could be mild dementia. If it's really extreme dementia they, they're probably not going to understand so you can tell them ten times that you're sending them back to the nursing home and they probably wouldn't understand. So. I think it's just gauging each individual, isn't it?* (*P27, H nurse, individual interview).* *P20: Some people are, very confused at their experience that they've had in the hospital. And some people are quite happy to be back, there is definitely some recognition there, they recognise familiar faces, people* *P21: I think generally people who've got some level of awareness of their environment do find it unsettling and, and take a while to find sort of their usual routine, don't they, they need more help and support* *(CH nurses, focus group).*
A new strategy identified for hospital to care home transition:- Identify appropriate proxy to act in the patient's best interests	Meeting psychological needs	*You know, somebody that might be mildly confused, you might be able to tell them, you know, their diagnosis, go through what that meant. Go through with them what treatment they had, which is generally what I kind of do at the point of discharge. But obviously with somebody that's very severe dementia you, you kind of can't really do that. So it's more about liaising with the family, um, and making sure that the nursing home are, understanding what's happened (P8, H nurse, individual interview).*

Nursing activities were aligned to three of the five suggested strategies for achieving patient engagement, however it was difficult to fully understand the extent in which care home residents were actively engaged. For example, although comprehensive assessments were conducted, it appeared the person with dementia had a passive role. Hospital nurses discussed the intricacies of engaging people living with dementia, with some adjusting engagement after assessing mental capacity. If engagement activities were considered to be stressful or were futile, hospital nurses sought out proxies, such as family and care home nurses, to act in the patient's best interest. I added a new strategy to reflect this activity. Activities that were concerned with patient engagement were mostly described in the context of keeping the person informed and there was no sense of bi-directional communication taking place. No activities were aligned with demonstrating respect for patients as partners in developing care plans. Further exploration in this area is required.

7.8. Family carer education

Naylor et al. (2017) describe family carer education as efforts to involve family carers in decision making regarding patient care and it includes preparing the family with the skills to care for the person after hospital discharge (Naylor et al., 2017: 3).

The suggested strategies to achieve this component include (Naylor et al., 2017: 5),

1. Involving family carers in planning care
2. Respecting and valuing family carers contribution to the team
3. Providing appropriate information and training to help family carers feel knowledgeable and confident
4. Referring family carers to community-based resources for support.

Care home nurses described how they lead on providing continuity of care when the person transfers back to their care home. Therefore, to make this care component more relevant to the hospital to care home transition, I have made a minor adaptation. I have added the words 'and care home nurse' to the name of this component, making it 'family carer and care home nurse education’. Where appropriate, I have added the words ‘and care home nurse’ to the proposed strategies. Table twenty-two illustrates the alignment of nursing activities with Naylor et al.’s, (2017) proposed strategies, with the adaptations as described.

Table Twenty-two: Care component, Family carer and care home nurse education

Definition: Involving family carers and care home nurses in decision-making regarding patient care and preparing the family and care home nurse with the skills to care for the person after hospital discharge.		
Naylor et al.'s (2017) strategies	**Nursing activity**	**Illustrative quotes from hospital and care home nurses**
Involving family carers and care home nurses in planning care	Involving families in care decisions	*Well we quite often have, erm, you know, have meetings with families if we decide at one of our MDT meetings that there's things that we need to discuss with families or, find out, you know, concerns that we've got or maybe changes to treatment or anything that we kind of have to change, get their take on it (P26, H nurse, individual interview).*
	Nursing assessment at admission and at discharge	*It's a discussion about how the client is at this point in time, are they back to baseline, and a two way discussion really between the care home and us as to what can be, what's best for that person really (P33, H nurse, individual interview).*
	Assessing for discharge	*We normally contact the care provider. which is mo- mostly it's the care home manager. They have to come in and making sure that they are still able to continue to meet their needs….They, they will do a, er, a follow-up assessment…because sometimes with the, with the most recent hospital admission the, they, their needs can change (P32, H nurse, individual interview).* *We do go out (to hospital) and see them, reassess them, you know, if you feel their condition's been changed drastically (P10, CH nurse, individual interview).*
Respecting and valuing family carers and care home nurses' contribution	Liaising with family to obtain information	*We do work with the families, yeah. We'll be keep ringing families often to find out, you know, how they are progressing in hospital, yeah, [ ] and if family says, oh no, we visited dad and he seems to be like he's not the same, um then you feel like, yeah we need to get out for a reassessment (P6, CH nurse, individual interview).*

to the team	Involving family in supportive care	*So, whether it's, they might have family that might come in and support us during those engagements of trying to get them packed… you know, so if it's the last day it's getting them packed up and ready to go (P12, H nurse, individual interview)*
	Assessing for discharge	*Good examples are when they (hospital nurse) communicates and asks are we happy to accept that person back, we may have to go out, and reassess. but its good when they have asked us ahead of time are we ready, is everything ok, everything set up for that person and just consulted us really (P9, CH nurse, individual interview).*
Providing appropriate information and training to help family carers and care home nurses feel knowledgeable and confident	No alignment of activities for training of families	
	Meeting physical health care needs	*The care home nurse will come in and see the patient, we'll talk them through, and then the nutrition team will be involved, because if it's somebody with a new PEG, the nutrition team are involved, with the care home, teaching and things like that, that's all sort of set up (P28, H Nurse, individual interview).* *So this person came with a new procedure been done, um and most of our nurses don't know how, a couple of them got the training early but this one was new device when they rang us, this patient is coming back, we told them that we need training for our staff and they have arranged for training (P5, CH nurse, individual interview).*
Referring family carers to community-based resources for support	No alignment of activities	

Nursing activities were aligned with two of the four strategies in achieving family carer education although I acknowledge there were also examples identifying inconsistency in these practices. No activities were described that aimed to prepare families for their caring role or referring them on for community support. There were some hospital and care home nurse activities which were aligned to strategies concerned with training of care home nurses to increase knowledge, and confidence in providing care continuity. It identifies hospital nurses work more with care home nurses than family in providing education.

7.9. Patient education

Naylor et al. (2017: 3) define patient education to mean "a continuous process of interactive teaching and learning with health care professionals. This should be based on assessment of patient's goals which aims to increase patient responsibility for their own health, encourage healthier lifestyle decisions and increase competencies to promote adherence to treatment, avoid adverse events, and promote independence."

The strategies proposed to address this component are (Naylor et al., 2017: 5),

1. Identifying and addressing health literacy and language
2. Presenting health information in easily accessible accurate and usable format
3. Confirming patient's understanding of instructions.

None of the nurses from either hospital or the four care homes discussed providing education to the care home residents they were working with. One senior nurse from Hospital A mentioned a letter about an estimated day of discharge which was given to patients shortly after admission. This was a communication document informing the patient of what to expect during admission and it was given to families of people living with dementia if it was considered more appropriate to do so. This was the closest example identified which met this care component, but it was not known how accessible the letter was for people living with dementia. As residents are having their care needs met by nursing staff, this may explain why this is a neglected dimension of care and requires further exploration.

7.10. Chapter conclusion

In this chapter I explored the extent to which nursing activities that hospital and care home nurses described, aligned with the model of best practice in transitional care created by Naylor et al. (2017). This demonstrated that nurses provide care which aim to align with many of these components of care. However, application of these strategies in achieving the components of care was not universal to all hospital and care home nurses. It indicates that the extent to which these components of care are conducted varies.

This analysis has identified that Naylor et al.'s, (2017) guidance does have relevance for hospital to care home transitions. Some minor adaptations are suggested to the model to make it more suitable for transition from hospital back to the care home. A new strategy was added to two care components as nursing activities were identified which did not align to existing strategies in the model. The naming of one care component was changed to reflect the care home nurse's role in providing care. 'Family Carer Education' was changed to 'Family Carer and Care Home Nurse Education'. Care home nurses were sometimes provided with educational support to address any skills deficit in providing ongoing care of the resident after hospital discharge. Figure five identifies the alignment and the adaptations made to the model.

There were categories (care components) which did not reach data saturation. This may indicate insufficient details were collected in relation to these care components, highlighting further investigation is warranted. However, the authors (Naylor et al., 2017) acknowledge that the degree of attention paid to each care component may vary depending on the patient needs. Some components were more extensively addressed than others for people living with dementia. This suggests achieving data saturation for each care component does not necessarily mean that optimal transitional care does not occur. The components of care which had an extent of alignment with nursing activities were care continuity, complexity management and patient well-being. This reflects that nurses were more engaged in activities which addressed meeting the complex needs of people living with dementia, attending to their well-being and ensuring continuity of care when the person transferred between the hospital and the care home setting.

A striking finding was the few examples of nurses engaging with the care home resident. When resident engagement was described, it was not in the spirit of active patient engagement as described by Naylor and her colleagues (Naylor et al., 2017). Shared examples were in the context of information giving, rather than participation in decision making and negotiating care goals. I added a new strategy to this component of care as nurses described proxy engagement with families or care home nurses.

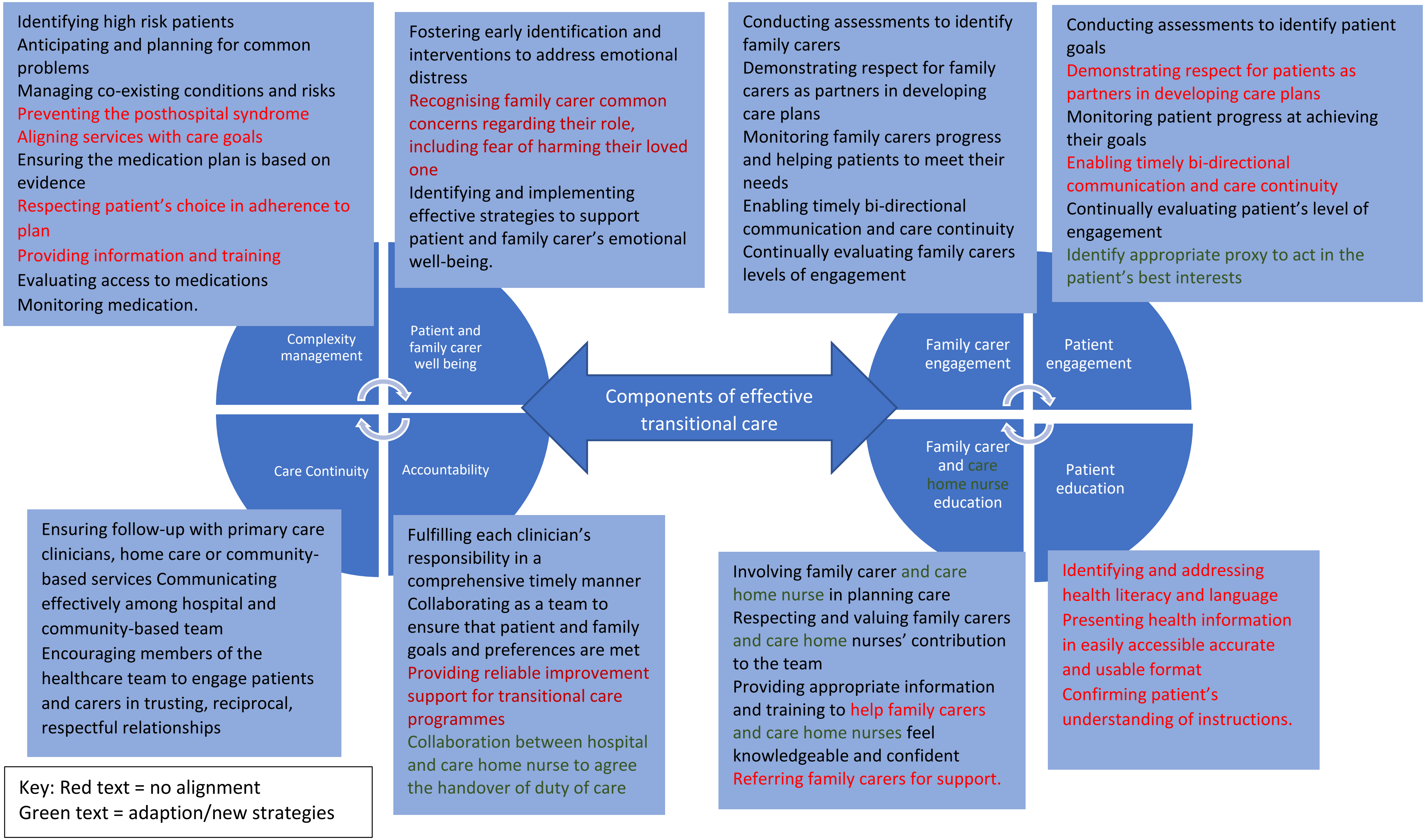
Other neglected components of care where there were no activities identified included patient education. Additionally, hospital and care home nurses did not assess carers' needs or involve them in education.

I identified an additional strategy for the accountability care component. Nursing activities relating to handing over duties of care were described. This was added to acknowledge this relevant strategy in the hospital to care home transition.

Some hospital and care home nurses described providing care that meets optimal transitional care practice, however there were some gaps in addressing all of the components. Naylor et al.'s, (2017) model of care is relevant for the hospital to care home transition for people living with dementia. It requires some minor adaptations to be useful for promoting a consistent approach to optimal nursing care at this transition for this client group.

The next chapter will summarise and synthesise the findings from the two findings chapters and will discuss their implications for policy, practice and research.

Figure Four: Diagram of nursing activity alignment to strategies in care component model (Naylor, et al., 2017)



Identifying high risk patients
Anticipating and planning for common problems
Managing co-existing conditions and risks
Preventing the posthospital syndrome
Aligning services with care goals
Ensuring the medication plan is based on evidence
Respecting patient's choice in adherence to plan
Providing information and training
Evaluating access to medications
Monitoring medication.

Fostering early identification and interventions to address emotional distress
Recognising family carer common concerns regarding their role, including fear of harming their loved one
Identifying and implementing effective strategies to support patient and family carer's emotional well-being.

Conducting assessments to identify family carers
Demonstrating respect for family carers as partners in developing care plans
Monitoring family carers progress and helping patients to meet their needs
Enabling timely bi-directional communication and care continuity
Continually evaluating family carers levels of engagement

Conducting assessments to identify patient goals
Demonstrating respect for patients as partners in developing care plans
Monitoring patient progress at achieving their goals
Enabling timely bi-directional communication and care continuity
Continually evaluating patient's level of engagement
Identify appropriate proxy to act in the patient's best interests

Ensuring follow-up with primary care clinicians, home care or community-based services Communicating effectively among hospital and community-based team
Encouraging members of the healthcare team to engage patients and carers in trusting, reciprocal, respectful relationships

Fulfilling each clinician's responsibility in a comprehensive timely manner
Collaborating as a team to ensure that patient and family goals and preferences are met
Providing reliable improvement support for transitional care programmes
Collaboration between hospital and care home nurse to agree the handover of duty of care

Involving family carer and care home nurse in planning care
Respecting and valuing family carers and care home nurses' contribution to the team
Providing appropriate information and training to help family carers and care home nurses feel knowledgeable and confident
Referring family carers for support.

Identifying and addressing health literacy and language
Presenting health information in easily accessible accurate and usable format
Confirming patient's understanding of instructions.

Key: Red text = no alignment
Green text = adaption/new strategies

Chapter Eight: Discussion

8.1. Introduction

In this final chapter I present a summary of the findings of hospital and care home nurse perspectives of their role in providing care to people living with dementia when they return to their care home after a hospital stay. I discuss how the findings from this study relates and adds to previous research. I consider the study's unique contribution to the literature and its strengths and limitations. I present the implications of these findings for policy, practice (including relevance for residential care settings) and research.

8.1.1. Summary of findings

The findings show hospital and care home nurses engage in four roles in providing optimal care for people living with dementia when they transfer back to their care home after a hospital stay. Nurses engaged in the exchange of information, assessed and met needs, worked with families and checked and organised medication. They conducted several nursing activities which make up these roles. Optimal care was provided when hospital and care home nurses understood the principles of dementia care, demonstrated leadership and autonomy and had positive relationships with each other. Hospital and care home nurses also wanted opportunities to develop ways of working together to improve practice.

Nurses perceived that people living with dementia have distinct needs at this transition. In meeting those needs there was interdependence between hospital and care home nurses. Nurses described the many challenges they face in performing their roles. Care home nurses were frequently excluded or not fully recognised as members of the healthcare team. This in turn impacted on their ability to fulfil their roles in providing optimal care. There was also variation in how nurses executed their roles. The environment in which they worked, the length of experience or the seniority of the nurses influenced this variation and such variation highlighted inconsistencies in how care was provided.

Hospital and care home nurses engage in several activities which aligned with many of the strategies for providing best practice in transitional care

(Naylor et al., 2017). Areas where they were not fully aligned include patient engagement, patient education, and family carer education. Naylor et al.'s, (2017) model of care applied well to the hospital to care home transition for people living with dementia. It only required some minor adaptations, such as adding a few strategies to some of the components and changing the name of one component to 'family carer and care home nurse education'.

8.2. How the findings relate and add to previous research

I now discuss how the findings from my study relate to the previous research on nursing roles in providing care at transition. I begin by outlining the research on the various nursing roles at transition and the challenges which have been previously described in implementing roles in providing optimal care. I conclude by outlining what is known about the facilitators for providing optimal care and what this study adds to this body of literature.

8.2.1. Nursing roles

I will now discuss how my findings resonate with previous literature on the multiple roles nurses engage in, the role of care home nurses, and the interdependent nature of hospital and care home nurses' roles in providing transitional care. I then discuss the variation in how nurses perform their role.

8.2.1.1. Multiple roles at transition

We know that hospital nurses engage in multiple roles in hospital discharge and transitional care (Watts, 2005; Rhudy et al., 2010; Mabire et al., 2015). They play a key part in assessing health and psychological needs and coordinating hospital discharge. This involves organising key resources such as medication, equipment and communicating with a wide range of people (Naylor, et al, 2004; Day, et al, 2009; Rhudy et al, 2010; Mabire, et al, 2015; Pellet, 2016). In my study four roles were found. Three of these roles - exchanging information, assessing and meeting physical and psychological needs and checking and organising medication - are consistent with these previous findings.

When a patient without dementia is returning from hospital to their own home, hospital nurses engage in patient and family carer education (Naylor et al., 2004; Foust et al., 2007). In a study comparing transitional care interventions delivered to people with dementia to those without dementia, little evidence of patient and family carer education was found (Prusaczyk et al., 2019). In my study no nurses described activities regarding educating people living with dementia and family carers. Prusaczyk, et al. (2019) suggest that this may be because hospital nurses do not consider patient and family carer education as necessary as their care needs will be met by nurses in the care home. However, we know that many family carers may still have ongoing involvement in providing care to their relative living in a care home (Puurveen et al., 2018) which may be enhanced by education and training.

8.2.1.2. Care home nurses' role in transitional care

There is much less research regarding the role of care home nurses in providing transitional care. We knew from this small body of research that care home nurses' roles involve coordinating with the hospital nurse to establish follow up care (Kirsebom et al., 2013; King et al., 2013). In my study I also found care home nurses engaging in these nursing activities.

A previous study of transitional care between hospital and care homes focused on the interdependent nature of exchange of information between these two care settings (Kirsebom et al., 2013). Furthermore, a previous ethnographic UK study investigating hospital discharge identified that interdependence of roles and agencies is required for hospital discharge to be effective (Waring et al., 2014). Interdependent functions that straddle hospital admission and post discharge were also recently identified by O' Hara, et al. (2020) in their analysis of transitional care. My findings also identified that hospital and care home nurses had an interdependent role which occurred across three of the four roles identified, exchanging information, assessing and meeting needs, and checking and organising medication. This interdependent role was considered particularly important in the care of people living with dementia, owing to the person's inability to communicate their own needs or relay accurate history of events prior to admission or the treatment received in hospital.

This interdependent nature of nurses' roles means optimising care has shared accountability. It highlights the importance of developing collaborative relationships between hospital and care home nurses. Yet the findings revealed there was insufficient time allocated for such development.

8.2.1.3. The variation in how hospital and care home nurses perform their role

Variation in how nurses perform their role is to be expected as it is known that the working environment affects nursing roles (Kieft et al., 2014). My findings support this, in that the particular ward environment hospital nurses worked in affected how they implemented their role. I also found variation occurred because of nurses' length of experience in the role or their level of seniority. These specific variations in nurses' roles have not been highlighted in the studies on transitional care from hospital to care homes. This is a useful addition to the literature, as this may account for some of the inconsistencies in the quality of information and care provided reported in this and other studies (Bauer et al., 2011; Digby et al., 2012; Kable et al., 2015; Bloomer et al., 2016; Kuluski et al., 2017).

Although research and practice guidance often support the use of standardised processes e.g., use of discharge pathways (Lees, 2013) this does present a dilemma in providing transitional care for people living with dementia. Optimising transitional care for people living with dementia frequently involved nurses applying a different approach to that of standardised procedures in response to the individual needs of the person.

8.2.2. Challenges described in implementing nurses' roles

Previous research emphasised the challenges in communicating information, having time to adequately prepare for transfers, nurse competency in responding to people living with dementia and nurses engaging people living with dementia and family carers when providing transitional care (Atwal, 2002; Nosbusch, 2011; Kable et al., 2015; Gilmore-Bykovskyi et al., 2017). I will now discuss each of these in turn.

8.2.2.1. Exchange of information

There is a long-standing challenge of inadequate information exchange at transition (Atwal, 2002; Nosbusch, 2011). The present study also found examples of inadequate information exchange between hospital and care home nurses. An NHS England initiative introduced in April 2018*, ‘the red bag scheme*’ has aimed to standardise information exchange between the two settings. Despite this, I found continued challenges with inconsistent practices reported with exchanging information. Other studies have identified the use of standardised instruments as useful in information exchange, although these studies were not focused on hospital to care home transitions (Nosbusch, 2011; Graham et al., 2013).

Both hospital and care home nurses highlighted that the provision of an electronic shared system for exchanging information would help to improve information exchange between them. Sharing electronic records has been found to improve medication continuity when a person is discharged from hospital. A systematic literature review identified that a secure electronic platform improved timely communication between hospital and primary care providers. However, it identified that primary care providers access to hospital providers’ information remained problematic (Tomlinson et al., 2020). Another study presented issues with the efficacy of shared electronic systems between hospitals and care homes. Hospital nurses in Sweden reported that despite having a shared system with care homes, problems existed as hospital nurses did not know what information for the electronic care summary was helpful to care home nurses (Kirsebom et al., 2013).

Findings from Kirsebom et al. (2013) highlight the need for both care settings to agree what information is required to ensure care continuity. In the present study, despite hospital and care home nurses stating they exchanged written information, supplementary information was frequently sought after transfer via phone calls. In some cases, information provided was inadequate identifying a discrepancy in expectations of what information should be provided.

In the present study hospital nurses reported difficulties in sharing patient-related information over the phone with care home nurses when the person was in hospital. They attributed this difficulty to confidentiality polices. Care home nurses considered they should have legitimate access and felt excluded. This finding appears unique to the UK, with only one reference to a UK public report (Professional records standards body, 2017). This warrants further investigation to identify how legislative practices/policies in other countries affect sharing information between hospital and care home nurses.

8.2.2.2. Timely prepared transfers

A common challenge to nurses fulfilling their perceived roles during this transition was the frequency with which transfers back to the care home were made with limited planning and inadequate notification for the care home to prepare (Kable et al., 2015 and Gilmore-Bykovskyi et al., 2017). In these circumstances rapid decisions were spurred by the need to create hospital bed capacity (Chenoweth et al., 2015; Kable et al., 2015; Gilmore-Bykovskyi et al., 2017). A recent US study investigating hospital to skilled nursing facility transitions noted that these rapid discharge practices commonly occurred in fragmented healthcare systems (King et al., 2017). In my study the negative effects of rapid discharge practice were a frequent challenge raised by both hospital and care home nurses. Nurses working on the short stay wards in particular faced this difficulty.

8.2.2.3. Competency of nurses to respond to needs of people living with dementia

From previous research we knew that hospital and care home nurses felt ill-equipped or prepared to respond to the emotional distress of people living with dementia (Kable et al., 2015; Gilmore-Bykovskyi et al., 2017). In contrast, in the present study hospital and care home nurses provided many examples of how they aimed to minimise distress and how they responded to distressed behaviour. Most nurses in my study had received dementia training and some were qualified mental health nurses. An increased emphasis on all health and social care staff being trained in person centred dementia care in the UK (Health Education England and Skills for Care, 2018) may explain why nurses in the present study felt better equipped.

Previous research has identified that care home nurses have a broad range of responsibilities which often require specialist skills to care for the increasing acuity of the care home population (Cooper et al., 2017). They also found that care home nurses experience challenges in accessing training and professional opportunities. Some care home nurses from the present study also discussed their struggles in accessing training to meet physical healthcare needs of their residents with dementia when they returned from hospital. Findings from the present study demonstrate that hospital and care home nurses perceive that care home residents have highly complex needs. Despite care home nurses' difficulties in accessing training, findings show that hospital and care home nursing activities aligned with best practice strategies (Naylor et al., 2017) in managing care complexity.

8.2.2.4. Engaging people living with dementia and family carers in care decisions

Previous research has found that people living with dementia are frequently not consulted in decisions about their transfer out of hospital to a care facility (Digby et al., 2012; Emmett et al., 2014; Gilmore-Bykovskyi et al., 2017). In the present study there was little evidence of patient engagement as is cited best practice (Naylor et al., 2017). Hospital nurses discussed evaluating a person's engagement based on mental capacity. Nurses did not report communicating with people living with dementia about having an active role in their care in either the hospital or care home setting. A recent systematic literature review on shared decision making for people living with dementia in extended care settings highlighted that people living with dementia value the opportunity to participate in decision making about their care (Daly, et al., 2018). Furthermore, it identified that as a person's dementia progresses and communication skills deteriorate, there needs to be a greater understanding of how to meet the shared decision making needs of people living with dementia who live in care settings.

We know that family carer engagement is viewed by all stakeholders as an important source of support to people living with dementia when they move out of hospital to a care facility (Emmett et al., 2014; Bloomer et al., 2016; Kuluski et al., 2017; Fitzgerald et al.,2011; Digby et al.,2012). In transitional care family engagement is also highlighted as best practice (Naylor et al., 2017). In my study hospital and care home nurses recognised the value of engaging with families as they provide additional resource to support the person living with dementia. That said only a few hospital and care home nurses discussed involving families in care decisions. This finding supports previous studies that further effort is required to meet this component of care (Bauer, et al., 2011; Bloomer, et al. 2016).

8.2.3. Facilitators for optimising care.

Previous research revealed that relationships between hospital and care home nurses can be adversarial (Kirsebom et al., 2013). Furthermore, hospital nurses have negative views of care home nurses, considering them as being less well trained (Reed and Stanley, 2003). Other studies have identified that problematic relationships between staff working in care homes and other health care professionals can result in fragmented care (Kupeli et al., 2016) and compromises effective and safe transitions (Robinson et al., 2012; Petersen et al., 2019). The present study identified similar issues, with negative assumptions made by nurses about each other's practice. However, findings in the present study also identified some positive relationships between hospitals and care home nurses. A few hospital and care home nurses viewed this to be a facilitator in optimising care and it supports research which has demonstrated how relationship development is critical for integrated working (King et al., 2017).

We know there are cultural differences between nurses who work in hospitals and those who are community-based (Hellesø and Fagermoen, 2010; Petersen et al., 2019). This was implied in the present study. I noted hospital and care home nurses used different terminology when referring to the person living with dementia. Hospital nurses used the word 'patient' and care home nurses used 'resident'. This suggests some cultural differences between the two nursing groups. Care home nurses also discussed the differences in the hospital and care home environment which influenced how care was delivered. Such cultural differences may contribute towards tense relationships and therefore opportunities to learn from and understand more about each other was identified as a facilitator for optimising care.

Two previous studies suggested that job rotation and regular meetings can facilitate nurse to nurse collaboration across different care sectors (Kirsebom et al., 2013; Lemetti et al., 2017). Care home nurses in the present study also considered job rotation, regular fora or workshops to discuss working together would help to understand the different working environments and optimise care. I also found that staff are motivated to develop closer working relationships and work in a more integrated way.

The ‘authority to act’ has been found instrumental in meeting the needs of people living with dementia receiving care in hospital (Handley et al., 2017). This realist evaluation found this authority coupled with knowledge led to staff responding to unmet needs. Authority in this case was not necessarily linked with seniority (Handley et al., 2017). I found similar examples of application of knowledge and use of authority when responding to resident distress. This ‘authority to act’ was linked to either seniority of role or years of nursing experience. Senior nurses in the present study implemented solutions which were caused by problems with the current healthcare systems of working. For example, they could address the time it took for take home medications to be organised for discharge. These solutions sometimes meant working outside of defined discharge procedures. A previous study of hospital and community-based nurses also found nurses using “informal methods to circumvent formal structures to compensate for deficiencies” (Hellesø and Fagermoen, 2010: 2). They noted that this could result in a two-tier system of care one which was influenced by local practice and the other by defined procedures. This may account for the variable practice in how nurses performed their role which was identified in my study.

To summarise, this PhD study contributes to the emerging knowledge on the topic of transitional care for people living with dementia. It adds to the existing body of international knowledge highlighting that both hospital and care home nurses have key roles in optimising care for people living with dementia when they transition between hospitals and care homes, whilst also adding the UK perspective. Common nursing roles were identified including exchanging information, working with families, meeting physical and psychological needs and roles in medication management. The study also identified that due to the complex needs of this client group there are common challenges in executing these roles which have also been found in other international healthcare systems. For example, the challenges of integrated information systems and working between the two care environments. The research identified how nurses try to solve some of these issues by developing local solutions to facilitate optimal care, a strategy that is also reported in other national and international studies. This study has identified that knowledge of the principles of dementia care is a key attribute for optimising care, a requisite which has been identified in the existing literature. Additionally, it emphasises the interdependent nature of the hospital and care home nurse role in providing optimal transitional care and the need for collaborative working between the two groups of nurses, also echoing the findings from other international studies.

8.3. Original contribution to the literature

This is the first study conducted in the UK that has explored perspectives of both hospital and care home nurses of the care they provide people living with dementia when they transfer back to their care home after a hospital stay. This has enabled a greater understanding of what they expect of each other and how they interact with and perceive each other's roles. It provided insights from the nurse perspective about the impact transitions has on people living with dementia and their families. This study has revealed findings which have not been previously reported in international studies of people living with dementia when they transfer from hospital to care homes. These include:

1) The distinct needs of people living with dementia when they return from hospital to their care home
2) Exclusions of care home nurses in accessing information and services to support optimal care of residents returning to their care home after a hospital stay
3) The adaptation of Naylor et al.'s (2017) care component framework for guiding hospital to care home transitions with a focus on people living with dementia.

8.3.1. The distinct needs of people living with dementia when they return from hospital to the care home.

The findings from my study highlights that the wait for transport and the journey back to the care home can be a particular source of stress for the person living with dementia. The issue of transport between settings has rarely been reported in previous research.

One recent study investigating transportation of older adults with cognitive impairment revealed very little empirical evidence on transportation, their study of shared transportation between a day care treatment centre and people’s homes identified several expressions of behaviours which interfered with safety. They reported this required skilled care from escorts and drivers in responding to these behaviours (Sefcik et al., 2019). The present study identified transportation to be an important topic in optimising care for people living with dementia. It was revealed that transportation required careful assessment by hospital nurses to ensure that transport was appropriate and met the needs of the person, acknowledging that people living with dementia have specific requirements.

Other studies on people living with dementia transferring from hospital and care homes have not acknowledged the role of family in transport. My findings add that family either providing it or acting as a care escort is often considered a better option for people living with dementia. It reduced waiting times and facilitated optimal times for transfer.

Other studies in this field have not identified journeys from hospital back to the care home. My study identified this could be distressing for people living with dementia if they did not return via a direct route. This arguably is not conducive for a person who may already be confused and disorientated. A finding in the present study noted care home nurses having a greater involvement in transporting their resident from hospital may optimise the care at this transition.

These findings of the inadequacy of current practice in providing transport for people living with dementia when they return to the care home after a hospital stay is an important addition to the literature, given the dearth of evidence in this area.

8.3.2. Exclusions of care home nurses’ access to information and services compared to other members of the healthcare team

My findings have noted that frequently care home nurses are excluded from the acute care system. As hospital and care home nurses rely on each other to perform their respective roles, this disadvantages care home nurses.

Despite care home nurses being a community-based health care provider, they are excluded from obtaining information about their care home residents whilst in hospital and do not have access to their shared electronic hospital-based record. Other members of the community-based healthcare team are able to access such records which highlights the disparity between them and other members of the team. Hospital nurses could also make direct referrals to allied health professionals and care home nurses could not. These issues appear to be missing in other studies on nurses’ roles in transitional care suggesting it maybe a UK issue.

Previous research has found issues of equity between hospital and care home nurses more generally. Spilsbury et al. (2015) reported care home nurses did not have the same access of training opportunities as nurses working in the NHS. Furthermore, Thompson et al. (2018) found care home nurses feeling excluded from the rest of the community based healthcare team. The lack of recognition of the challenges that care home nurses face in providing community-based healthcare have also been illuminated in the COVID-19 pandemic (Mitchell and Hill, 2020). The findings from these studies along with the present study highlight the care home nurse role has a complex interface with the healthcare system.

8.3.3 Adaptation of care component framework (Naylor et al. 2017) for care home transitions

To understand if the nurses’ roles aligned to best practice in transitional care an existing care component framework was used. This is the first study to use this framework as a tool for aligning nursing practice to care components. The existing care component framework (Naylor et al., 2017) was developed for hospital to own home transitions and some minor adaptations were required to account for the care home transition and for those living with dementia. Adaptations to different care cultures and contexts are welcomed by the authors (Naylor, et al., 2017). Despite the framework being developed in the US it was found to be relevant for us in the English care system, albeit with some adaptations to terminology. This involved the addition of suggested strategies and the renaming of one care component. Additionally, it is believed this is the first study to make adaptations to the framework so that it can be applied to the care home transition. This study found that the adapted framework could be applied to the hospital and care home transition and those who live with dementia. This is an important addition to the literature for the nursing profession highlighting its potential for adapting this framework to other care contexts.

8.4. Strengths and limitations of the study

8.4.1. Strengths of the study

The key strengths of this study are how I have involved diverse stakeholders throughout the project, gaining both hospital and care home nurses perspectives and my own knowledge of the context. I will now discuss these in turn.

8.4.1.1. Involvement of diverse stakeholders

I involved stakeholders throughout. Firstly, my Project Advisory Group provided support in developing study materials. I wanted to ensure that data collection tools were accessible to nurses. They also provided valuable insights when discussing my findings. It was particularly valuable to hear feedback from people living with dementia and family carers. For example, a person living with dementia in the group discussed assumptions made by nurses. She expressed that assumptions were being made by hospital nurses that care home nurses were fully prepared to accept their resident back. A family carer mentioned the variation in nursing practice and how, in her own experience, she had seen how this led to inconsistent care. These discussions were helpful in affirming some of my interpretations.

8.4.1.2. Gaining perspectives of both hospital and care home nurses

Gaining both hospital and care home nurse perspectives is a strength of this study. This has enabled important insights into the interdependent nature of the two roles and to understand the nursing care provided. It has facilitated an exploration of transitional care, telling the story of nurses' roles across the transition pathway. Triangulating these roles with best practice guidance is also another strength. This has revealed perceptions into where best practice is being delivered and where it can be improved.

8.4.1.3. My knowledge of the nursing context

Although an insider position may bring bias to a study, my understanding of the nursing context is one of this study's strengths. Nurses appeared comfortable talking to me as a nurse. It was evident when reviewing transcripts that some nurses identified me as a nurse, as phrases such as *'you know as a nurse yourself* 'were found. This may have contributed to nurses' being open in reporting their accounts of their practice. The expressions of their thoughts and feelings about their role, allowed for an interpretation of what influences implementation of their roles. As a nurse I spoke the same 'language' I did not have to clarify terminology or ask for procedures to be explained. Given the pressures on nurses' time this allowed for interviews to be focused on answering the questions. Although some might argue the disadvantages, in that assumptions can be made by either the researcher or the participants. This might result in researchers not fully exploring concepts they think they know, or participants not giving full explanations, as they assume knowledge of the researcher (Khaliza and Aizan 2016). On balance, I believe the advantages outweighed the disadvantages.

I considered my dementia knowledge was also a strength. For example, my understanding of the likely stressors for people living with dementia enabled me to probe and explore the nurses' role in responding to the specific needs of people living with dementia.

8.4.2. Study limitations

Study limitations include sampling, methods of data collection and timing of the study.

8.4.2.1. Limitations with sampling

It was my original intention to recruit care home sites within the geographical location of the two participating hospitals. This was to achieve an understanding of perspectives of nurses who were likely to interact with each other and be familiar with each other's transitional care procedures. However, many of the care home sites in those geographical locations were unable to participate. Only one of the care homes interacted with one of the hospitals. Understanding if hospitals had relationships with the care homes in the study was therefore not possible. In retrospect, to better understand relationships between hospitals and specific care homes, I could have approached care homes who had experienced recent transfers from the participating hospitals. However, despite care home nurses in my study interacting with three different hospitals very similar processes were described by them. There was little variation in the two participating hospital sites, but as previously described most variation occurred across ward types.

The use of purposive sampling and a snowball sampling technique has limitations in that those who were interested in transitional care and dementia care were more likely to come forward or be referred. This interest may be reflected in the demographics of my sample. Two thirds had over ten years of nursing experience, and several had a leadership role. This may bring some bias into the data. I found their experience influenced the care they provided. A sample which included newly qualified nurses may have yielded different perspectives of role. It could be argued that the experience of nurses and their leadership qualities has allowed for deeper insights about nurse perspectives on what facilitates nursing roles to provide optimal care at this transition.

My study was from only two perspectives, hospital and care home nurses. It was intentional to seek only nurses' perspectives of their role, to understand what they as a professional group understood. However, on reflection, broadening the scope of the study to include the views of other professional groups, health care assistants and paid care workers regarding the nursing role in transitions may have provided greater insights.

8.4.2.2. Limitations of data collection methods

My initial preference was to use focus groups and I have previously explained that these were difficult to organise due to the busy clinical environment and the ability to release nursing staff to attend. As a result, the data collected were from three different methods; individual and dyadic interviews and focus groups. Although exchanging focus groups for interviews has been done before in other qualitative studies, it is important to acknowledge that the different methods influence the data collected (Baillie, 2019).

In the focus groups and dyadic interviews, the interaction between participants facilitated a further exploration of issues, as different points of views were raised or challenged. These discussions were often more emotive to that of individual interviews, although frustration was detected in both focus groups and individual interviews. In the focus groups, nurses frequently developed a consensus about issues discussed. Developing consensus can be related to composition of the group, particularly if there are similarities in experience (Greenwood, et al., 2014). In my study nurses participating in groups worked for the same organisations and in the case of care home nurses were providing care for the same people, so similarities in experience was observed. A focus group only study may have revealed slightly different data. However, it was still possible to detect the sense of agreement amongst nurses by looking for agreement or disagreement of perspectives across the whole data set.

I have highlighted that during my research I observed the emotions that nurses expressed during interviews. I witnessed non-verbal behaviours and could hear differences in tone during their recordings. On reflection, video recordings of interviews or groups may have been a more useful method in being able to observe these behaviours and emotions more accurately, rather than relying on memory, notes, and audio. However, practical challenges of organising video recording and gaining consent for the use of video could have been problematic.

Whilst conducting the deductive content analysis, I realised I had not explored all the components of effective transitional care in great depth during data collection. For example, I did not probe to ask nurses about their role in relation to patient education which may have prompted them to say if they executed such roles or not. Although I had used the guidance to develop the topic guide, I feel I should have added specific questions to ensure that I explored more fully the components of care. On the other hand, I wanted nurses to tell me things from their perspective without prompting and not to dominate the interviews.

In addition to interviews and focus groups, observational methods of data collection would have added further richness to the data. This method would have enabled me to witness first-hand the role of nurses during hospital to care home transitions. I initially considered this, but I envisaged potential difficulties of being present when transitions were taking place. However, nurses told me that care home residents were regularly admitted to hospital. On reflection, it may not have been as difficult as first thought, although gaining ethical approval may not have been as straightforward.

Conducting a document review of patient records to explore nurse actions and roles, may also have been a useful supplementary method of data collection. A recognised limitation of document review is the insufficient detail documents can provide because they were not produced for the research agenda and may not provide sufficient detail for answering a research question (Bowen, 2009). However, it may have proved useful for confirming the quality of information provided at transition, and further exploring the interaction between nurses and other professionals.

8.4.2.3. Timing of the study

There was a limitation in the timing of my study. My findings suggest nurses had mixed views about the success of the ‘red bag scheme’. The scheme had recently been introduced at the time of data collection and may be now more embedded in the healthcare system.

8.5. Implications

8.5.1. Implications for policy

The findings have several implications for policy. These include reiterating a need for integrated health and social care; national care home bodies and nursing organisations to lobby for the status of care home nurses; NHS hospital Trusts and care home providers to work together and share accountability for transitional care between the care settings.

8.5.1.1 Integrated health and social care national policy

There is now an urgent need for policy makers to address how care homes can be integrated into the healthcare system. Over time there has been a policy neglect of social care. According to figures from the Nuffield Trust (2019) local authority funding has recently halved in real terms. As local authorities are responsible for assessing and providing social care needs to those in greatest need, this negatively impacts on the provision of social care. The increase in demand for social care for the rising number of older people and those with long term conditions has meant that local authorities have revised their eligibility criteria, restricting access to support for many with social care needs (Kings Fund, 2019). There have been repeated delays, at least five in the last two years, in the government's publication of the social care green paper which sets out a consultation for social care reform (Atkins, 2019). These delays highlight this was not a government priority. This is of concern as the social care and healthcare systems are intrinsic, in that a quality social care funded system is crucial for a performing NHS (NHS confederation, 2020).

The COVID-19 pandemic has illuminated this social care neglect and has also exposed the inequities between health and social care. It highlighted that the lack of linked datasets between hospitals and care homes impeded the ability to protect people most at risk (Hanratty et al., 2020). It identified that nurses and other workers in care homes were not seen as a priority compared to NHS colleagues, with NHS colleagues being prioritised for provision of personal and protective equipment and testing (Mitchell, 2020). A recent editorial also highlighted that care home staff are often an 'after thought' identifying they were initially left out of the campaign 'clap for the

NHS’, failing to recognise the work of the care home sector in the COVID-19 pandemic. The slogan was later changed to ‘clap for carers’ (McGilton et al., 2020). This amplifies that the care home sector is not viewed equally as members of the broader healthcare team, despite them being providers of complex healthcare. A finding also identified in my study.

It is a complicated issue, in that care homes are largely privately owned, and it could be argued that care homes need to provide adequately for their staff and residents. However, care home nurses are delivering health care to older people which would historically have been provided by the NHS (Robbins et al., 2013). It identifies the pressing need for health and social care integration at a strategic level.

The NHS long term plan (DoH, 2019) has identified the need for radical change in how health and social care is delivered. The formation of Integrated Healthcare Systems (ICS) was announced. Currently eighteen have been developed in England. These are partnerships which bring together commissioners of NHS services with providers and local authorities across a defined geographical area to take responsibility for planning and managing integrated care. It is too early to predict how these will progress, they are locally led systems and differ across the country in respect of partnership maturity. Currently these partnerships have no basis in legislation with no formal powers of accountability (Charles, 2020). Although there is a national framework for their development, the fact they are locally led could potentially mean a variation in integrated working across the country, which is currently observed. There is an urgent need for these partnerships to develop and include providers in the care home sector.

8.5.1.2. The status of care home nurses

There is an important policy implication about the status of care home nurses. Care home and nursing organisations need to continue their lobbying of raising their profile. There is evidence that care home nursing is viewed as lower status to that of hospital nursing (Reed and Stanley, 2003; Thompson et al., 2017). Along with evidence that suggests that many graduate nurses do not opt for routes working with older people in care homes, (Stevens,

2011) it can fuel an assumption that care home nursing is viewed as less attractive and low status.

This negative view of care home nursing has been recently recognised by the Nursing and Midwifery Council (NMC) who provided a statement supporting the contribution of social care nurses and clarifies those nurses working in social care are as skilled as all other nurses on the register (NMC, 2019). The Queen Nursing Institute have recently highlighted the specialist skills care home nurses need to perform their role and launched a national care homes nurses’ network. Additionally, the Chief Nursing Officer for England recently appointed the first nurse advisor on care homes. Such initiatives are evidence of the effort to rebrand the status of care home nurses (Ford, 2020). This is timely, as a finding in my study noted a perception that hospital nurses did not understand the care home environment, this along with evidence that graduate nurses not opting to work in the care home sector, suggests nurse education programmes do not prepare nurses for working in social care. Nurse education programmes need to address this to elevate the profile of care home nursing.

Furthermore, the charity ‘Care England’ which represents the independent care sector need to continue their lobbying to policy makers to ensure the integration agenda moves forward. This integration should also consider care homes having access to shared hospital records of their care home residents.

8.5.1.3. Health and social care integration at the local level

Local health and social care economies must be integrated and develop policies and initiatives that encourage collaborative working between the hospital and care home sector. Developing integrated working is a well-known challenge, the fact that there is such a mix of private providers adds to that complexity. A systematic review of integrated working between care homes and health care services indicated that formal structures need to be in place for successful health and social care integration (Davies, et al., 2011).

Commissioners need to work with providers to create capacity for the development of nurse to nurse collaboration. Hospital and care home nurses in the present study described time pressures and a heavy workload. Managers in NHS Trusts and care homes must work together at a local level to consider how these pressures can be managed. There needs to be an appreciation that building relationships takes time and resources if nurse to nurse collaboration is to be improved.

A recent UK study identified that there is variation in how NHS and care home staff work together. This realist evaluation of three health and social care economies identified what supports effective working to improve health outcomes in care homes (Gordon et al., 2018). Although the study did not focus on transitional care it highlighted that it takes time for NHS and care home staff to work together to develop a common purpose and shared understanding. It noted that relationships were often less developed in time-limited care home initiatives when little time was allocated for staff to learn together. It observed that shared professional development opportunities were instrumental in introducing service innovations supporting optimal care provision.

Furthermore, a US study of transitions from hospital to skilled nursing facilities noted that an integrated healthcare system had shared goals of a patient centred approach, shared accountability and sought feedback from stakeholders. It identified such integrated systems of care impacted positively on transitions (King et al., 2017). Although the healthcare systems are different in the US, the findings from this study identified that shared understanding is an important element for integrated working. However, shared understanding can only be realised if hospital and care home nurses are given opportunities to work together.

Findings from these studies support job rotations and bringing hospital and care home nurses together for shared professional development could be a way to start the process of hospital and care home nurse collaborative working.

8.5.2. Implications for practice

The findings have several implications for transitional care practice. These include involving people living with dementia and their families in care, reducing inconsistencies in practice, addressing misaligned hospital processes and the continuing professional development of registered nurses. Additionally, these findings also have practice relevance for staff working in UK residential care homes, (care homes without on-site nursing).

8.5.2.1. Involving people living with dementia and families in care

The findings identify the need for a greater focus on how nurses can actively involve people living with dementia and their families in negotiating goals of transitional care. This could be addressed by making this a prominent issue in dementia training. People living with dementia and their families could be encouraged to give their views on how this might be achieved.

8.5.2.2. Reducing inconsistencies in practice

Hospital and care home nurses need to consider how to reduce inconsistencies in care. Hospital and care home nurses should be provided with opportunities to meet together to discuss how they can reduce variation in their practice and provide more consistency.

Care home staff could be encouraged to go into hospitals to support their residents, this strategy could be further explored by hospital and care home managers for feasibility.

Providing enhanced health care in care homes is required to avoid hospital admission where possible, but these initiatives need to be more widespread. Not all care homes have access to this level of support (Baylis and Perk-Baker, 2017). Receiving care in their care home would facilitate a consistent level of care provision to care home residents.

8.5.2.3. Address misaligned hospital processes

There is a need to address the coordination of take-home medication and the provision of appropriate and timely transport from hospital. As these perceived issues were reported at both hospitals in my study it suggests the need for NHS Trusts to consider their operational procedures to better align these processes. Hospital and care home nurses, people living with dementia and their families should be consulted in these quality improvement plans.

8.5.2.4. Continued professional development of registered nurses

There is a need to educate and develop newly qualified nurses in implementing transitional care interventions, by either providing training or guidance which meet the needs of people living with dementia. This might involve sessions focusing on best practice interventions in preceptorship programmes. Continuing professional development of all nursing staff providing transitional care also needs to be addressed, including nurses working in social care. Offering job rotations in both sectors and regular meetings would support increase in knowledge and understanding of each other's roles.

8.5.2.5. Relevance of findings for residential care homes

Section 1.2.2 of chapter one highlighted the growing acuity and complexity of need in the care home population in both residential and nursing homes. The significant growing number of people with dementia living in residential care homes living with co-morbidities who are also high users of hospital care was emphasised. The social care workforce in UK residential care homes is pre-dominantly comprised of care support workers, senior care workers, and home managers (Skills for Care, 2019). Studies investigating the roles of health and social care workforce identifies qualified and unqualified staff have had to upskill to meet the increasing complex needs of the care home population (Spilsbury and Meyer, 2005; Wild, 2011). The shortage of nursing staff and the difficulties in recruiting nurses in care homes has led to them reviewing care tasks and delegating more of these to care home support workers (Heath, 2012). Moran et al.'s (2011) review of the literature identified four domains of the support worker role: direct care, meeting residents' care needs'; indirect care, for example, contacting relatives, administrative roles such as organising appointments and taking phone calls; and a facilitation role, facilitating interprofessional communication on behalf of the person. These domains overlap with the roles of care home nurses described in my study of transitional care. Additionally, previous studies have identified the care home manager as having a central role in residential care in the assessment of health care needs of care home residents, as they make key health care decisions and organise appropriate health care (Gladman, 2010;

Schreuders et al., 2020). Some of these roles are also identified by nurses and many of the implications for policy, practice and research presented have relevance for staff working in residential care homes. The role of care home staff in transitional care from hospitals to residential care homes would be worthy of further research.

8.5.3. Implications for research

There are several implications for research. These include the efficacy of educational interventions, identifying most appropriate transport arrangements, the effectiveness of job rotation and hospital and care home nurse fora, exploring the role of the nurse from different professional perspectives and investigating the sharing of resident-related information between hospitals and care homes.

Further research could include the development and testing the effectiveness of the care component model of care into a training package. For example, a national Delphi study could be conducted to gain consensus on the model. This could be followed by a co-designed training package involving local stakeholders to ensure it is developed for the local context. The training package could be piloted and evaluated to determine if formal training improves transitional care.

The use of transport in dementia care is an underdeveloped area of research (Sefcik et al., 2019). Further research is required in understanding more about appropriate forms of hospital transport for people living with dementia. For example, future research might include observational studies that explore the journeys back to care homes from hospital. The responses of people living with dementia to the different transport options could be further explored by interviewing all the people involved, including the person with dementia, their families, nurses and transport providers. This could give a better understanding of which methods are more suited for this client group.

Further research could explore some of the suggestions for practice change such as job rotations and regular meetings/fora to see if they increase collaboration and relationships. For example, future research might use realist evaluation to examine their usefulness. A local network could be developed to include care home and hospital managers, care home and hospital nurses to work together on developing quality improvement initiatives such as including care home nurses in discharge planning. These initiatives could be evaluated to examine the effects of them in the different contexts within the locality. The network could also be evaluated to establish if they facilitate integrated working.

As this study focused only on registered nurse perceptions of the nursing role, future research could include the exploration of a range of stakeholder perspectives. For example, a survey could be conducted with other professionals and paid care workers to understand what they view to be the role of the nurse in this transition and what could optimise care.

It would also be useful to understand more about how policies and procedures affect the sharing of care home resident information between hospital and care home staff. For example, an investigation of legislative practices and policies in other countries might establish if this is a UK issue and might inform effective ways of sharing sensitive and confidential information.

8.6. Chapter conclusion

This is the first study to explore UK hospital and care home nurses' perspectives on their role in providing optimal care for people living with dementia who return to their care home after a hospital stay.

Findings highlight that care home nurses are not integrated members of the healthcare team. There is a need for policy to address the status of care home nurses and take action to ensure they are treated as equal members. This is particularly salient and timely as the COVID-19 pandemic has amplified the policy neglect of social care and the challenges that exist for care homes who are large providers of healthcare. Findings support the urgency for moving forward the health and social care integration agenda.

8.7. Thesis Conclusion

Achieving safe and effective transitional care for people living in care homes is of concern as many live with dementia and other comorbidities which poses a risk of hospital admission. Although internationally there is emerging evidence of this care transition for people living with dementia, very few studies have been conducted in the UK. We have insufficient knowledge in the UK about the extent of the nurses’ role in providing transitional care for people living with dementia who transfer between hospital and care homes. This study aimed to explore the role of hospital and care home nurses in providing optimal care at this transition.

This qualitative exploration of perspectives adds to previous research that providing transitional care is challenging, that care home residents with dementia have highly complex care needs and transitions are difficult for them. Although there are limitations of the study, it provides an important step in identifying that hospital and care home nurses share interdependent roles in providing this care. It found that nurses are meeting cited best practice in several areas and do have knowledge and skills in responding to the needs of people living with dementia. However, many challenges exist, and optimal care relies on positive relationships between hospital and care home nurses and the integration of care home nurses into the healthcare system. The research adds to the existing calls for urgent action for central and local government to address the inequalities between social and health care and to fully support the integration of care home nurses into the healthcare system.

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Appendices

Appendix one: Published systematic review

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BMC Geriatrics

RESEARCH ARTICLE Open Access

Stakeholder perspectives of care for people living with dementia moving from hospital to care facilities in the community: a systematic review

Angela Richardson*, Alison Blenkinsopp, Murna Downs and Kathryn Lord

Abstract

Background: People living with dementia in care homes are regularly admitted to hospital. The transition between hospitals and care homes is an area of documented poor care leading to adverse outcomes including costly re-hospitalisation. This review aims to understand the experiences and outcomes of care for people living with dementia who undergo this transition from the perspectives of key stakeholders; people living with dementia, their families and health care professionals.

Methods: A systematic search was conducted on the CINAHL, ASSIA, EMBASE, MEDLINE, PsychINFO, and Scopus databases without any date restrictions. We hand searched reference lists of included papers. Papers were included if they focused on people living with dementia moving from hospital to a short or long term care setting in the community including sub-acute, rehabilitation, skilled nursing facilities or care homes. Titles, abstracts and full texts were screened. Two authors independently evaluated study quality using a checklist. Themes were identified and discussed to reach consensus.

Results: In total, nine papers reporting eight studies met the inclusion criteria for the systematic review. A total of 257 stakeholders participated; 37 people living with dementia, 95 family members, and 125 health and social care professionals. Studies took place in Australia, Canada, United Kingdom (UK), and the United States of America (US). Four themes were identified as factors influencing the experience and outcomes of the transition from the perspectives of stakeholders; preparing for transition; quality of communication; the quality of care; family engagement and roles.

Conclusion: This systematic review presents a compelling case for the need for robust evidence to guide best practice in this important area of multi-disciplinary clinical practice. The evidence suggests this transition is challenging for all stakeholders and that people with dementia have specific needs which need attention during this period.

Trial registration: PROSPERO Registration Number: CRD42017082041.

Keywords: Dementia, Hospital, Care home, Transition, Family carers, Healthcare professionals, Discharge

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Background

People living with dementia are frequent users of hospital services [1], with bed occupancy rates as high as 25% at any one time [2]. The most common reasons for admission are injuries sustained from accidents and falls, urinary tract and respiratory infections and exacerbations of other chronic health problems [3]. For over a decade there has been considerable attention paid to hospital discharge processes, with particular emphasis on seeking to avoid unnecessary admissions and reduce delays in discharge, in order to alleviate pressure in the health system [4]. Yet people living with dementia continue to experience delayed hospital discharges and when discharged, feel inadequately prepared; therefore it is not surprising hospital readmissions are common [2].

Internationally, the transition between hospitals and care homes has been highlighted as a concern; with several studies noting care at this transition requires improvement [5–8]. In the UK, over two-thirds of care home residents are reported to be living with dementia [9]. Although information is limited about the use of hospitals by care home residents, Quality Watch, a UK major research programme, published a report following their analysis of hospital admission rates. Their findings imply that care home residents experienced 40–50% more emergency admissions than the rest of the population over the age of 75 years [10].

It is widely reported that transitions in care for older people lead to error, breaches of patient safety, rehospitalisation and mortality [11–13]. As a result, older people require additional resources in order to transfer safely from hospital in order to avoid these post-discharge adverse events [13, 14]. The components of care that are particularly found to be lacking during transfers to care homes for older people are patient and family engagement in planning for the transfer [5, 6]; timely prepared transfers [7]; follow up care [8]; and communication about health and medication between settings [6]. These can all lead to frequent hospital readmissions [15]. These studies were not particularly focused on the experiences of people living with dementia.

Internationally, different terminology is used to refer to the care provided when a person transfers out of hospital back to the community. Improving this care has received most attention in the US and Australia. The term ‘transitional care’ appears to have emerged in the US in the 1980’s [16]. It refers to a broad range of actions including proactive, collaborative planning, service identification, and follow-up activities delivered to ensure continuity of healthcare to improve patient outcomes when people move between levels or locations of care, most notably from the hospital to the community [17, 18]. The Australian government announced in 2004 the development of the ‘Transition care program’. This is a time limited initiative which enables older people with lower level support and care needs, to receive care in residential or community settings, to gain independence and confidence either to return home, or make decisions about moving into a more appropriate supported accommodation [19]. The concept of ‘transitional care’ is relatively new in the UK, where there appears to be a much narrower focus on discharge processes and planning. There is now recognition that discharge planning processes are time-limited by the length of hospital stay, from admission to the day of discharge [20] and are only one element of transitional care.

The bulk of transitional care research taking place in North America, Australia and Europe has been conducted with older people being discharged to their own homes, with more recent work including a focus on people living with dementia [21–23]. Where the transition between hospital and care home has been studied [5–8], people living with dementia are often not included. Despite the policy emphasis on person-centred care, we know relatively little about the experiences and outcomes of people directly affected - people living with dementia and their family carers, nor their health and social care professionals. A UK report has indicated that coordinated transitional care practice is variable for people living with dementia, who move between care settings [24]. There is now a compelling argument to review the literature, in order to understand more about the experiences and outcomes of this transition for people living with dementia.

The aim of this review is to identify and synthesise evidence from the published literature on the experiences and outcomes of care from hospital to a care home (or similar care facility) from the perspectives of people living with dementia, their families and health and social care professionals.

Methods

This systematic review follows the guidance set out in the Centre for Reviews and Dissemination guidance for systematic reviews [25]. We registered the review with PROSPERO (International Prospective Register of Systematic Reviews) (PROSPERO 2017) [CRD42017082041].

Search strategy

A CINAHL search strategy was developed without any date restrictions which was adjusted to run on five other electronic databases: ASSIA, EMBASE, MEDLINE, PsychINFO, and Scopus (See Table 1 for CINAHL strategy). The terms ‘Dementia’ or

‘Alzheimer’s disease’ or ‘cognitive impairment’ was used in combination with ‘transitional care’, or ‘discharge planning’, or ‘transfer, discharge’, and with ‘hospital’ or ‘care home’, or ‘residential care’ or ‘nursing home’ or ‘skilled nursing facility’. The search was run in April 2018. Additional papers were identified by hand searching the reference lists of included papers. No date restrictions were applied as we were interested in including relevant older studies. The oldest study retrieved for full text review was 1996 although this was excluded as it did not meet the inclusion criteria.

Table 1 (CINAHL search strategy)

	Search terms /combination	Results
1	(MH “Dementia+”)	(56,809)
2	(MH “Alzheimer’s Disease”)	(25,305)
3	“cognitive impairment”	(14,859)
4	1 OR 2 OR 3	(66,823)
5	(MH “Transfer, Discharge”)	(4,696)
6	(MH “Transitional Care”)	(482)
7	(MH “Discharge Planning”)	(4,403)
8	5 OR 6 OR 7	(9,359)
9	(MH “Hospitals+”)	(95,412)
10	(MH “Residential Care +”)	(6,320)
11	“care home”	(2,099)
12	(MH “Skilled Nursing Facilities”)	(2993)
13	(MH “Nursing Homes+”)	(23,732)
14	9 OR 10 OR 11 OR 12 OR 13	(124,718)
15	4 AND 8 AND 14	(76)

Inclusion and exclusion criteria

This review focuses on both ‘experiences’ and ‘outcomes’ of transitional care. It was at times difficult to determine differences between ‘experiences’ and ‘outcomes.’ For this review, the team defined the term ‘experience’ as capturing the emotional and psychological responses to being involved in the transitional care process, for example feeling ‘unprepared’ or ‘frustrated’. ‘Outcomes’ related more to; effects, consequences and impact during or following the transition, for example ‘fully engaged in discharge planning’ or ‘communication failures’. Studies were included if they reported:

The experiences and/or outcomes of care for people living with dementia or cognitive impairment (‘dementia’ and ‘cognitive impairment’ as defined by the authors of the individual studies), moving from hospital to a short or long term care setting (e.g. sub-acute, rehabilitation, skilled nursing facilities (SNF), care homes, including those returning to their care home after a hospital admission).

Outcomes and experiences of the people living with dementia and/or their families were reported separately from those without cognitive impairment.

Actions such as discharge planning from hospital to a care facility and any intervention or service people received during and following transition or the period waiting for long-term care placement.

Papers were excluded if:

The majority of patients/residents referred to in the study were older people without cognitive impairment (we were led by the authors of the individual studies descriptions' of 'older' and 'cognitive impairment').

The majority of patients/residents were being discharged back to their own home (own home refers to a domestic setting, those returning back to their care home for example were not excluded)

The study did not report on experiences or outcomes of care

They were not written in English

They did not report empirical findings that were published in peer review journals.

Data extraction and quality appraisal

All references retrieved were exported to Endnote reference management software version X7 and duplicates removed. Titles and abstracts of studies were read and screened by one reviewer. Two reviewers then independently read all retained papers. The decision to include or exclude papers was agreed by consensus by both reviewers. A third reviewer was available if consensus could not be reached; recourse to a third reviewer was not required. Data were extracted from the included papers using a pre-determined set of criteria, which was developed by the review team after testing with a small number of papers. The final information extracted was, location, study setting, study type, study aim, study participants, main findings.

Each paper was assessed for quality independently by two reviewers, using checklists that had been developed and used by other authors [26] [27]. Only the checklists for qualitative and intervention papers were required for the current review. A point is awarded if the paper meets each criterion on the checklist, a maximum of six for qualitative and five for the intervention studies, high scores signifying higher quality (Table 2). Criteria were weighted to define higher quality studies as previously described in Lord et al. [27]. Qualitative papers were characterised as higher quality if they used a clearly defined recruitment method, had clearly stated inclusion and exclusion criteria, standardized data collection and involved two or more independent raters in data analysis (criteria 2,3,5). Intervention studies were characterised as higher quality if they appropriately allocated participants to intervention and control groups, ensured all participants who

Table 2 Quality Assessment Tool. [27]

Quality assessment tool for Qualitative studies

(1) Were the aims of the research clearly stated?

(2) Was a clearly defined method of recruitment used and explicit inclusion/ exclusion criteria described?

3) Was the process of data collection explained clearly? Was data collection standardised?

4) Did the researchers attain saturation of data?

(5) Was the process of data analysis sufficiently rigorous, i.e. ≥2 raters, some method of resolving discrepancies?

6) Have the findings been validated by participants?

Quality assessment tool for Intervention studies

(1) Were participants appropriately allocated to intervention and control groups? (was randomisation independent?)

(2) Were patients and clinicians as far as possible 'masked' for treatment allocation?

(3) Were all patients who entered the trial accounted for and an intention to treat analysis used?

(4) Were all participants followed up and data collected in the same way?

(5) Was a power calculation carried out, based on one or more outcomes of interest?

entered the trial were accounted for and collected data and followed up all participants in the same way (criteria1, 3, 4). Quality assessment was agreed by consensus; a third reviewer was available if consensus could not be reached, but was not required.

Results

After removal of duplicate papers the number of retrieved titles and abstracts screened was 2111, and of those, 28 potentially met the inclusion criteria and were subject to full text scrutiny. Nine papers met the inclusion criteria (PRISMA Fig. 1). The majority of studies meeting the inclusion criteria used qualitative methodology. This may be due to the nature of the review question; focusing on perspectives. Eight of the papers reported qualitative studies and the ninth was a pre/post intervention evaluation. The nine studies are summarised in Table 3 (Study

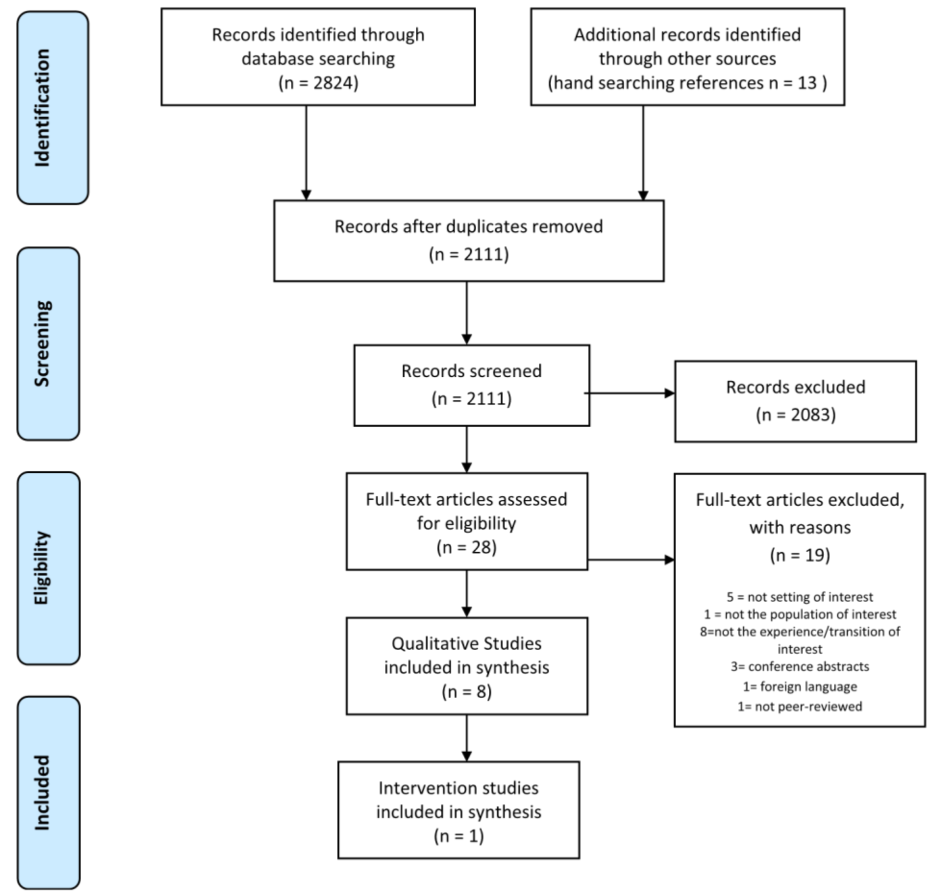

Fig. 1 PRISMA Diagram

Table 3 Description of settings/ services

Study and country	Study setting(s) / care service	Description or definitions of settings and or services	Transition points where perspectives are elicited
Bauer et al. (2011) [28] Fitzgerald et al. (2011) [29] Australia	Rehab facility (n = 8) Residential care (n = 8)	Rehabilitation facility, short-term restorative care before discharge back home or to residential care. Residential care – Long term care facilities providing high and low level care.	Family carers interviewed 2 months after discharge about their experiences.
Bloomer et al. (2016) [30] Australia	Geriatric evaluation and management facility	Provides rehabilitation to optimise function and determine future care needs. Majority of patients are transferred from acute care, a third of patients move to residential care.	Family carers of people with dementia were interviewed after admission into the Geriatric evaluation and management facility. Experiences were elicited about transitioning through the system from acute hospital.
Digby et al. (2012) [31] Australia	Geriatric rehabilitation facility (sub-acute facility)	A facility providing in-patient evaluation, and management of older patients with complex needs, most transferred from acute care setting.	People living with dementia interviewed between 1 and 5 days after transferring from hospital to the facility.
Emmett et al. (2014) [32] UK	Three general elderly care wards in two hospitals	Acute hospital care providing medical care for short-medium term acute episodes of care.	Patient and family carer interviews were conducted at point of discharge and 3 months post discharge. Health and social care perspectives elicited about discharge planning and decision-making.
GilmoreBykovsky et al. (2017) [33] USA	11 Skilled nursing facilities (SNF)	SNF's provide high level of medical and nursing care. Services are provided for a limited time but can be more longer-term.	Nurses were interviewed about care when people had transitioned from hospital into the skilled nursing facility.
Kable et al. (2015) [34] Australia	Acute tertiary facility GP Practice Residential aged care setting	Acute hospital care Community care Long-term care facility.	Both hospital based and community based health care professionals' perspectives of transitional care were elicited about care at the transition points of leaving hospital into the community.
Kuluski et al. (2017) Canada [35]	Hospital setting, (alternate level of care (ALC))	Patients who are fit for discharge but are waiting for long term care placement or community support.	Family carers perspectives were elicited whilst the patient was receiving the alternative level of care.
Renehan et al. (2013) [36] Australia	Transitional Care programme which was called 'Transition Care Cognitive Assessment and Management Pilot' (TC-CAMP)	Dedicated (short term) beds within a residential aged care facility, used specifically for people living with dementia who were medically fit to be discharged from hospital and would be transferring to long term care.	Health and social care professionals from all of the transition points; hospital, TC-CAMP and discharge destination care home. Family carers perspectives were gathered post discharge from the TC-CAMP.

settings and service descriptions) and Table 4 (Study methods and quality appraisal).

Studies were published between 2011 and 2017. Six of the papers were from Australia, [28–31, 34, 36] with two reporting findings from the same study [28, 29], one was from the US [33], one from the UK [32] and one from Canada [35].

Just two of the studies elicited perspectives of people living with dementia [31, 32]. Both authors interviewed people living with dementia; N = 8 and N = 29. Emmett et al. [32] additionally carried out ethnographic observations over 111 days. Renehan et al. [36] analysed the care records of people living with dementia to determine whether the transition programme was helpful to those residents with behavioural and psychological symptoms. Using interviews and or focus groups, five studies included the perspective of family members [28–30, 32, 35, 36] and four studies sought the views of health and social care professionals [32–34, 36]. The combined number of participants from each category was 37 people living with dementia, 95 family members and 125 healthcare professionals. A range of health and social care professionals were represented these included: medical staff working in hospitals and the community [32, 34]; allied health care professionals [32, 34, 36]; social workers, health care assistants and a professional advocate [32]. The largest professional group were nurses including those working in hospitals [32, 34, 36], community care facilities [33, 36] and in GP practices [34]. Staff working in residential care homes were included in two studies [34, 36]. Renehan et al's [36] study also included a range of staff from the transition care programme which included personal

Table 4 Table of studies, methods and quality appraisal

Study	Methods	Participants	Aims	Main findings	Quality appraisal					
					1	2	3	4	5	6
Bauer et al. 2011 [28] Fitzgerald et al. 2011 [29]	Semi-structured interviews	25 carers	Understand family carers experience of discharge planning, support, and what improvements could be made.	Breakdown in communication: lack of coordination, Hospital staff having poor capability for caring for people with dementia. Inadequate preparation, undervaluing family carer as a resource.	✓	✓	✓	✓	✓	✓
Bloomer et al. 2016 [30]	Semi-structured interviews / conversation approach	20 carers	Explore the experience of carers through hospitalisation and rehab with a view to transitioning to residential care.	Families found the process difficult. Decisions about moving into care was challenging, carers would like to be better informed, concerns about the care provided whilst in hospital.	✓	✓	✓	x	✓	x
Digby et al. 2012 [31]	Semi –structured interviews	8 people living with mild to moderate dementia, transferred in the preceding 5 days	Understand the experience of people living with dementia (plwd) who are settling in after transfer from acute hospital to sub-acute facility.	People felt disorientated. Participants felt patronised by staff and unsettled by the loss of control in the environment. Family support was a great consolation.	✓	✓	✓	x	x	x
Emmett et al. 2014 [32]	Ethnographic approach using observation, interviews and focus groups.	35 health and social care prof 29 patient interviews and cases 28 nominated relative	Explore the role of relatives during the discharge planning process and when decisions are made to discharge plwd from hospital either back home or to long-term care.	Roles relatives play; advocates, information gatherers, and care takers which included assisting. Lack of information inadequate preparation. Conflicts of interest between relatives and patients.	✓	✓	✓	✓	✓	✓
GilmoreBykovsky et al. 2017 [33]	Focus groups and semi structured interviews	40 licensed nurses from SNF's	To examine SNF nurses' perspectives regarding experiences and needs of plwd during hospital-to-SNF transitions.	Inadequate preparation of person, being excluded form care decisions. Unprepared receiving environment. Role of timing of transition. Inadequate information about social and health needs and behaviour related symptoms. Staff feeling ill-equipped to provide safe care. Misalignment between hospital pressures and transitional care needs of patient.	✓	✓	✓	✓	✓	✓
Kable et al. 2015 [34]	Focus groups	33 Health care professionals (HCPs) of which 21 hospital staff 12 community staff	Explore HCP perspectives on the discharge process and transitional care arrangements for plwd and their families.	Acute staff experienced difficulty caring for people with dementia. Patients were over sedated on return. System pressures to discharge. Inadequate preparation time for work capacity issues. Inadequate communication between health professionals working in different settings.	✓	✓	✓	x	✓	x
Kuluski et al. 2017 [35]	Semi structured interviews	15 family members across 12 interviews	Understand the hospital experience of carers of patients who require an Alternate Level of Care, (waiting for long-term placement).	Inconsistent quality of care, non-medical needs and characteristics ignored. Families addressing the gaps in the system. Confusing process.	✓	✓	✓	✓	✓	x
Renehan et al. 2013 [36]	Interviews, focus groups, file audits,	11 cases of which 8 had completed records, 7 family members took part in the qualitative evaluation 17 staff from the hospital, facility and destination facility	To evaluate the transitional care cognitive assessment management pilot. Identify barriers and enablers to implementation.	Significant reduction in agitated behaviours once moved to the transitional facility. Adequate communication provision and valued the clinical nurse consultant. Discharge destination facilities reported information timely and thorough.	Intervention x	x		x	✓	x

assistants, diversional therapists, team leaders and managers.

Study settings where transitional care took place were varied but the majority were short-term stay settings. The description and definitions of settings or services and the transition points where the authors elicited perspectives can be found in Table 3. The majority of studies focused on the care provided at transition, including discharge planning, how decisions are made, and the processes involved in the transfer.

Methodological quality

Seven of the qualitative studies were rated as higher quality, with scores ranging from four to six (Table 4). The one lower quality study score [31] reflects that insufficient information was given on the process of analysis and whether at least two raters had been involved. The pre/post intervention evaluation [36] was also rated as lower quality, meeting only one out of the five criteria, the low score relates to not having a comparison group and experiencing administrative issues resulting in incomplete records and measures only available for eight out of the 11 records.

Narrative thematic analysis

The findings extracted from the papers were read multiple times. A constant comparative method of continually moving between the findings of each study was utilised. One reviewer coded the findings. These were grouped into related categories. A second reviewer checked these for accuracy. Four recurring themes pertaining to outcomes and experiences were identified from the included papers: preparing for transition; quality of communication; quality of care; carer engagement and roles of the family. Some themes were overlapping, for example preparation for transitions was closely linked to the quality of communication given when preparing for transfer. Quality of communication also linked to carer engagement. A summary of the experiences and outcomes from the different perspectives can be found in Table 5.

Preparing for transition

Preparing for the transition was discussed in five studies; by family carers [28, 29, 32], health and social care staff [33, 34] and briefly mentioned in one study reporting the experience of people living with dementia [31] . Perspectives were varied. The degree of feeling prepared was closely related to the quality of communication exchanges between stakeholders. For family members, being insufficiently prepared for being involved in discharge meetings undermined their ability to give an informed opinion about discharge decisions [32]. There were examples of carers feeling that the lack of communication relating to discharge arrangements left them feeling totally underprepared for their role, post transfer [28, 29]. One study reported the impact of not preparing the person properly contributed to a stressful experience for the person living with dementia: by allowing them to think they were being discharged home when in fact they were transferring to a care facility and by not allowing enough time to understand the decisions made [33]. People living with dementia in Digby et al's study [31] were unable to recall the preparation involved, but many admitted to feeling disorientated by the move.

Hospital pressures to react to the increase in admissions meant that health and social care professionals felt additional pressure to discharge because the bed was required [33, 34]. This resulted in clinicians not being able to formulate detailed discharge documentation and transfers to care facilities being arranged quickly, without sufficient consultation. Insufficient time for the facility to prepare adequately, either in organising the environment, ordering specialist equipment, comfort items or medication were reported. There were also examples of transfers after hours, late at night which was neither conducive for the person with dementia or the receiving care facility. All of this militated against a successful transitional experience.

Quality of communication

Communication issues were reported by all stakeholders in all but one of the studies [35]. The quality of the communication between stakeholders was mostly described as inadequate. Breakdowns of communication between family members and the hospital were reported. Family carers felt that they could be better informed about the discharge planning, follow up care after discharge, and the options to assist with decision making during discharge planning [28].

Care decisions were often made on the basis of insufficient information of health status, care needs, dementia related behavioural symptoms, and the social history of the patient, which subsequently affected the quality of the transition for the person with dementia and or their family. This was reported both by families [28, 29] and by staff [33]. This proved difficult in areas such as individualised care planning, responding appropriately to the person with dementia and providing continuity. This was stressful for the person with dementia and their family, and could affect their ability to settle in the changed environment. Healthcare professionals also felt a poorly executed transition from hospital due to lack of information reflected badly on the care home who could be viewed as inefficient and disorganised, resulting in a poor start to the care home experience for both people living with dementia and their family [33].

Health and social care professionals fail to communicate adequately with the person with dementia about discharge planning and outcomes [31–33]. Examples were reported of people with dementia being excluded from care decisions about a transfer to the SNF [33]. Digby et al. who interviewed eight people living with dementia revealed they were often not consulted about their care and they felt powerless and unsettled in their new location [31]. An example cited by Emmett et al. describes the anger felt by a patient who was excluded from decision-making about her future care needs [32].

In their study of family carers and health and social care staff, Renehan et al. reported positive communication practice [36]. Six of the seven family carers felt they received adequate information, which was done by regular meetings, and contact with the Clinical Nurse Consultant prior to admission, during the stay and at point of discharge. This clinician undertook the assessments for the service. Two of the seven families reported difficulty getting hold of the clinician but families appreciated having access to a named professional. Responses from social care professionals from the discharge destination facilities were also favourable stating information was comprehensive and timely. The provision of designed documentation, which detailed a full social and medical history of the person, was greatly valued by the facility staff.

Quality of care

The majority of the studies noted inconsistency in quality of care and the capability of healthcare professionals to care for people living with dementia when transitioning to a different location. This often resulted in unsatisfactory experience and outcomes for all stakeholders involved.

Families expressed concerns about standards of care in hospitals, in particular with assumptions being made

Table 5 Summary of experiences and outcomes from different perspectives

Stakeholders engagement perspectives	Theme: Preparing for transition		Theme: Quality of communication and roles of family		Theme: Quality of care		Theme: Family	
	Experiences	Outcomes	Experiences	Outcomes	Experiences	Outcomes	Experiences	Outcomes
People living with dementia.	Unable to remember preparation.	Disorientated by move.	Feeling unsettled and powerless. Feeling angry	Excluded from care decisions and decision making.	Feeling patronised and unsettled.	Lack of personal empowerment. Lack of understanding from staff.		Family support provides comfort.

Family carers	Insufficient preparation	Undermined ability to give informed opinion re planning. Lack of communication.	Feeling communication could be better. Appreciation of access to named professional.	Breakdown of communication between family and hospital. Care decisions made on insufficient information. HCPs fail to communicate adequately with person with dementia. Some reported adequate communication attending regular meetings. Difficulties getting hold of clinicians.		Assumptions made by HCPs about psychosocial needs of the people living with dementia. Concerns about standards of care. Some reported reduction in agitation, improved socialisation and health outcomes.	Feeling unappreciated and frustrated when excluded. Tension and family conflict about care decisions. Stressful experience leading up to discharge.	Families filling gaps in care system helping with hands on care and advocacy. Family support provides comfort to the person with dementia.
Health and Social care professionals (HCPs)	Person with dementia feeling stressed. HCPs feeling pressured. Unsettling for person with dementia.	Not preparing the person properly, unable to understand event. Quick transfers, insufficient time to prepare documentation. No time to organise environment and order equipment. Transfers late in day.	Stressful experience for person with dementia and family. Poor start to care home experience for person with dementia and family.	Care decisions made on insufficient information. HCPs fail to communicate adequately with person with dementia. People with dementia excluded from care decisions. Difficulties with individual care planning and providing care continuity. Affect the ability of the person to settle in new environment. Judgment of care facility as being inefficient. Some reported timely and comprehensive information.	Feeling ill-prepared and ill-equipped about how to care for people living with dementia.	People living with dementia returning to facility over sedated Not having original health care needs met. Under reporting of behavioural symptoms. Insufficient workforce to provide care.	Conflicts of interests between family members and person living with dementia.	Smoother transition when working with families. Working with family members could be difficult.

about the psychosocial needs of the patient, the person's by Digby et al. also described a lack of understanding on level of function, (such as maintaining activities of daily the part of healthcare professionals in the facility, as they living whilst in hospital) and involvement of the family reported often feeling patronised and unsettled by the [28, 30, 35]. The people living with dementia interviewed lack of personal empowerment in the environment [31].

Care facility and hospital healthcare professionals reported having difficulties in caring for people living with dementia particularly those with behavioural symptoms. In one study, [34] residential care staff reported that people living with dementia often returned from hospital over-sedated, without having their original health needs addressed. They attributed this to hospital based healthcare professionals' inability to respond to the needs of the person living with dementia. Hospital based healthcare professionals in turn felt they lacked knowledge in caring for people living with dementia and felt specialist support was lacking.

Nurses in a SNF also admitted to feeling ill-equipped to care for people living with dementia who were transferred from hospital. This they attributed to the lack of detailed information about the person's behaviour and the supportive care which was required [33]. Some care home nurses felt that hospitals under reported behavioural symptoms. As a result the care home did not have the workforce capacity to respond appropriately to some of the needs of patients transferred from hospital. Residential care home staff also reported that when transfers happened during out of office hours, there was no registered nurse on duty [34].

Positive outcomes for people living with dementia who transferred into the specialist transition care programme were reported [36]. The quantitative results indicated a reduction in the frequency of agitated behaviours on the Cohen Mansfield Behavioural inventory compared to the scores when the person was in hospital. However, some of the data were incomplete so some caution must be exercised with interpreting this finding. There was some qualitative verification of this finding, with families reporting reduction in agitation, improved socialisation and health outcomes following transfer from hospital to the facility.

Carer engagement and roles of the family

All stakeholders agreed that families have an important role to play in transitions from hospitals to care facilities with all studies discussing this topic. Stakeholders noted that successful transitions occurred when family members were involved prior, during and after the transfer. Families often filled the gaps in the care system and were noted to be actively involved in providing advocacy, facilitating communication, helping with personal care, providing much needed stimulation and helping to prepare the environment [30, 32, 35]. Both Fitzgerald et al. and Digby et al. reinforced that family support and regular presence provided comfort to the person living with dementia [29, 31]. Nurses working in an SNF also noted a smoother transition when opportunities arose to work directly with the family in preparing the person for transfer to the facility [33]. Despite this recognition of the valuable role of families, they were often not consulted about discharge arrangements [28, 34] . The lack of family involvement and exclusion in decision making led family members to feel frustrated and unappreciated [32].

Moving from hospital to care home for the first time can be particularly challenging for family members. Tension and family conflict about decisions were common [30] and conflicts of interests between patients and relatives regarding funding care were noted [32]. Working with families was difficult from the healthcare professional perspective, the hospital nurses in Reneham et al's study found supporting families a challenge due to the multiple roles that they had [36].

Family carers found the time leading up to discharge within the hospital environment, the associated decision making about moving into a care facility, the care processes and systems particularly stressful. [28–30, 32].

Discussion

This is the first review of stakeholders' perspectives on the transition for people living with dementia from hospital to community care settings. A striking finding is the paucity of studies (n = 8) eliciting stakeholders' perspectives on this experience and on the outcomes of care. The majority of these studies were conducted in Australia and relatively recently. Despite the development of the concept of transitional care in the US, few of these studies on transitional care examine stakeholder perspectives of this transition for those living with dementia.

In this review we created a narrative synthesis of stakeholders' perspectives on transitional care of people living with dementia moving from hospital to a care facility. We established four inter related issues of importance to all stakeholders: adequate and inclusive preparation for transition; the need for good quality and timely communication; quality of care and family carer engagement. The studies in the review have noted there are shortfalls within these four categories, from the perspective of all stakeholders, which negatively impacts on all stakeholders involved. Findings also highlight facilitators for improved experience.

Although there are reviews that have focused on hospital discharge processes for people living with dementia [37–39] this review examined additional transitional care activities with emphasis on moving to and being received by a care facility. Our findings are consistent with these reviews, in identifying some of the barriers to successful transition out of hospital for people living with dementia. Furthermore they identify specific issues relating to transferring to a care facility. It highlights a number of clinical practice issues resulting in unsatisfactory experiences, which could be improved upon.

Evidence from this review demonstrates many people living with dementia are often transferred to an alternative setting or care for either rehabilitation or to wait until a long-term care placement can be found. This has clinical implications as opinion is mixed whether multiple relocations for people with dementia causes further problems and should be minimised [40]. Whilst experiencing this alternative location in care or waiting for placement, the person with dementia and their family were often receiving care that did not meet the needs of individuals. Family members often act as advocates and provide 'hands on' care whilst the person is in hospital or a transition setting but conversely are not included in decision making about care. These findings are also reflected in a review of proxy decision-making by families of people living with dementia, which noted family carers were excluded from decisions made in hospital [27].

Health and social care professionals working with family members are fundamental in the care of people living with dementia. Successful transfers were reported when health and social care professionals were able to effectively engage with families. One study in this review demonstrated positive outcomes for people living with dementia when they were referred to a dementia specialist transition care program [36]. Increased family satisfaction was achieved when families had a named professional with whom they could liaise and communicate with both in the hospital and following transition into the facility. The practice of having a dedicated professional responsible for discharge planning is also supported in national UK guidance but is not specific about their role after transition [41].

Health and social care professionals also felt they did not have the skills to manage the complexities involved in caring for people with dementia. It is commonly recognised that when people with dementia are unwell or are in a place which is unfamiliar their response may be one of heightened anxiety and agitation [42], yet examples were given of health care professionals not being able to respond to this with non-pharmacological approaches and resorting to medication. This is not unusual, studies have reported that care of people living with dementia in hospital is often task orientated, delivered with little social engagement, sometimes with a lack of compassion and inappropriate responses to agitated behaviours such as the use of security services [43]. Given that this review has identified many people living with dementia often receive short-term care due to delays in arranging care to their final destination, it is important that staff in these areas have the skills to provide competent care.

System pressures resulting in sudden transfers were often a barrier to providing sufficient information between settings. Assumptions were made by hospital based healthcare professionals that facilities could respond quickly with little appreciation of the time required to prepare the right environment and arrange supplies of essential medication. Similar findings were noted in a Swedish study [44] that examined hospital and care home nurses' views of older people transfers between settings. It found that transfers back to nursing homes were commonly done with limited planning, late in the day with little communication between nurses in either setting.

The emphasis on rapid turnover of patients is also not conducive to the patient with dementia. Kitwood's theory of person centred dementia care [45] and the need to prevent behaviours such as outpacing and depersonalised care regimes suggests that such hurried transfers with little preparation of the person can significantly undermine a person's well-being. System pressures also place staff under considerable stress. Findings of this review echo those in an English study by Connolly et al. [46], who reported practitioners were conflicted by competing internal and external pressures, which undermined their professionalism, caused frustration, and resulted in de-personalisation of care.

These findings have noted that how discharge activities are implemented can have unintended consequences for the care the person receives at the care facility. There is a sense in the literature that systems and processes between settings can be adversarial. An appreciation of perspectives of both ends of the pathway, and a focus on working together may help to facilitate better transitional care experiences.

Limitations of the included studies

There are some limitations of this review which need to be considered when interpreting the findings. The studies reviewed used limited methods of data collection, mostly focus groups and interviews, although these methods yield rich data, the researchers are relying solely on the interpretation of the participants. Only two studies used supplementary data collection methods. Observational methods were particularly lacking, and one of the reasons may be the practicality of being able to observe transitional care in practice. Most studies used purposive sampling, relying on volunteers to come forward to participate in research, their views may not represent those who did not volunteer and may be skewed due to having negative experiences of the transition. A further limitation is the variation in the care facilities that were studied. There was a range of providers from government funded, to privately owned profit and non-profit facilities. Operational and clinical procedures, staff ratios and training are likely to be varied. Additionally all the studies were from a limited number of western countries with different health care systems and findings may not be transferable to other healthcare contexts.

Limitations of this review

Although a comprehensive search was undertaken from six databases and hand-searching only eight studies were found in this review. More studies from grey literature and non-peer reviewed journals may exist, but not necessarily of high quality. This does limit the conclusions that can be drawn.

Conclusions

The findings point to this key transition for people living with dementia being an under-researched area fraught with clinical care concerns. Despite the policy focus on person-centred care few studies seek the perspective of people living with dementia and their families. Yet we found that diverse stakeholders share common concerns about care during this transition including the need for: adequate preparation for transfer; effective communication between settings and stakeholders, quality care whilst their long term care needs are arranged and family engagement throughout. We identified areas of best practice which can help to guide care. There is a compelling need for further research in order to improve the experiences of the transition from hospital to care facilities for people living with dementia, their families and health care professionals.

Abbreviations

9pt?>ALC: Alternative level of care; HCP: Health and social care practitioners; PLWD: People living with dementia; SNF: Skilled nursing facility; TC-CAMP: Transition care cognitive assessment and management pilot; UK: United Kingdom; US: United States of America

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Authors' contributions

AR, AB, MD, and KL took part in developing the review question. AR led on data screening; AR and KL quality appraised the papers and undertook the analysis. AR led on writing the paper; AR, AB, MD, and KL contributed to and commented on the final draft. All authors read and approved the final manuscript.

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Publisher's Note

Appendix two: Project advisory group

Members of project advisory group

- Specialist nurse in dementia care based at an Acute Trust
- A care home manager
- A care home nurse – clinical lead
- One former carer of a person living with dementia
- One former carer of person living with dementia, whose relative resided in a care home.

Summary of comments made on project materials

Comments made on participants information and consent forms

One family carer gave comments on simplifying the language used in the participant information sheet and the recruitment poster.

Comments on topic guide

One family carer gave comments on topic guide, wanted to add a question on what nurses considered as the barriers to their role in providing care at transition. This was added to version two.

Hospital nurse mentioned nurses would not use language like components of care which were in the original topic guide. Care home manager agreed with hospital nurse’s comments. Care home nurse advised simplifying the topic guide, and refrain from using words like ’goal’. Incorporated feedback into version two

Appendix three Participant consent form

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PARTICIPANT CONSENT FORM

Nurse focus groups/interviews

Optimising the transition for nursing home residents living with dementia who return to their place of care after discharge from hospital

Angela Richardson, PhD Student, School of Dementia Studies, University of Bradford. Richmond Road, Bradford. West Yorkshire. BD7 1DP. a.richardson13@bradfprd.ac.uk 01274 236389

Please initial box

1. I confirm that I have read and understand the information sheet dated ………… for the above study and have had the opportunity to ask questions and have had these answered satisfactorily . ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason or rights being affected. ☐
3. I agree to the interview / focus group being audio recorded ☐
4. I agree to the use of anonymised quotes in publications. I understand researchers will remove personal details to ensure that I cannot be identified from any quotation ☐
5. I agree to participate in this study ☐

______________________	______________	______________________
Name of Participant	Date	Signature
______________________	______________	______________________
Name of Researcher	Date	Signature

Appendix four: Participation information sheet

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Optimizing the transition for nursing home residents living with dementia who return to their place of care after discharge from hospital.

PARTICIPANT INFORMATION SHEET

Focus Groups and semi-structured interviews for hospital-based nurses

Introduction

We would like to invite you to take part in a research project. We are approaching you because we understand that you have experience in providing care of people living with dementia who are admitted to hospital from nursing homes. It is important before you take part you understand what is involved so please take the time to read this and talk to others if you wish.

What is the purpose of the study?

The purpose of our project is to determine the nursing care required when a nursing home resident living with dementia is returning to their care home from hospital. We are also interested in finding out the facilitators of best practice with this transition.

Who is organising and funding this project?

This project is part of a PhD. The PhD studentship is funded by The Alzheimer's Society and the University of Bradford

Why have I been invited?

We are inviting registered nurses who work at your hospital and have experience of facilitating care of people living with dementia who are admitted to hospital from nursing homes.

Do I have to take part?

No. taking part is entirely voluntary. If you do you will be given this information sheet to keep. You are free at any time to withdraw without giving a reason. Withdrawal or non-participation will not affect your employment.

What will happen to me if I take part?

You will be asked to participate in one discussion group with other nurses from the hospital where you work. If you are unable to attend this group meeting you are welcome to participate in an individual interview with the researcher at a more convenient time/location.

What do I have to do?

The focus group or interview will last approximately one hour, and refreshments will be provided. There will be two researchers there to help the discussion and make sure everyone is heard. The discussion will be audio recorded so we make sure that we do not miss anything that is said. The discussion will cover your experiences of caring for nursing home residents who have dementia who are admitted to hospital and about the care you think nurses should provide to ensure that their transition back to their nursing home goes smoothly. We will also try to identify facilitators which support your role in providing care.

These focus groups or one to one interview will be audio recorded, and anonymously written up. The recordings will be deleted once they have been transcribed. You will be offered the opportunity to review your own transcript for comment and alteration.

What are the possible benefits of taking part?
We hope you will find taking part in the group interesting. The information we get may help to develop nursing practice. We also hope it may go on to improve the support offered to people with dementia and their families when transitioning from hospital to a nursing home.

Are there any disadvantages from taking part?
We do not anticipate that there will be any disadvantages to taking part except for the inconvenience of making time for the focus group or interview, but it is possible that some topics discussed may be upsetting. If this is the case, you can speak to one of our team (details below) or we can find someone in your organisation who you can talk to.

Will my taking part in the project be kept confidential?
All interviews are confidential and anonymous so your name and your organisation's name will not be disclosed to anyone else and neither will you be identified in any report or publication.

What if I have concerns about this research?
If you wish to complain or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or University of Bradford's complaints mechanisms are available to you. Please contact the student's principal supervisor Professor Murna Downs m.downs@bradford.ac.uk

What will happen to the results of the project?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send this to you. You will not be identified in any report or publication.

Who has reviewed the project?
All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed and approved by The Health Research Authority on 27/11/2017. IRAS project number 234370

How to contact the research team
If you have any further queries please do not hesitate to contact: Angela Richardson, PhD Student. a.richardson13@bradfprd.ac.uk 01274 236389

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for considering taking part or taking time to read this sheet.

Appendix five: Recruitment poster

UNIVERSITY of BRADFORD

PhD Research Project

Alzheimer's Society
United Against Dementia

Optimising the transition from hospitals to nursing homes for people living with dementia

Are you a qualified nurse working with people living with dementia in a nursing home?

We are seeking nurses who have worked at the nursing home for a minimum of three months who would be willing to share their knowledge and experience. This is a great opportunity to be involved in developing dementia care nursing practice.

Study

This study involves talking to nurses in a group or individual setting about their experiences and views about the care of people living with dementia who are returning to the nursing home after a hospital admission and what nursing care they require to ensure they transfer safely.

The focus group or interview will take approximately one hour and refreshments will be provided.

For further information please contact:
Angela Richardson,
PhD Student at the University of Bradford.
a.richardson13 @bradford.ac.uk   01274 236389
Principal supervisor: Professor Murna Downs.

Doctoral Training Centre: Transitions in Dementia Care

Appendix Six: Participant demographic form

Background/demographic information

Interview/ Focus group date:

Interviewer/ Facilitator's name:

Participant number:

Please circle the answer that best describes you.

1. Are you: Female Male
2. Which of these age groups describes you?

   18-30 31-40 41-50 51-60 61-70

3. How would you describe your ethnicity using the categories on the attached sheet?

4. What is your first language?

   Please describe here…………………………………………………………………………………

5. Which year did you qualify as a nurse? …………………………………………………

6. What are your nursing qualifications (e.g. adult nurse, mental health nurse)?
   ………
7. Which qualifications do you have?

   Diploma Bachelor's degree Master's degree PhD

   Please let us know about any further relevant nursing qualifications. (e.g nurse prescriber, advanced practice)

   ………

   ………

8. Have you received any specific dementia training? Yes No

   If yes, please give brief details (e.g. length of course) ………………………….

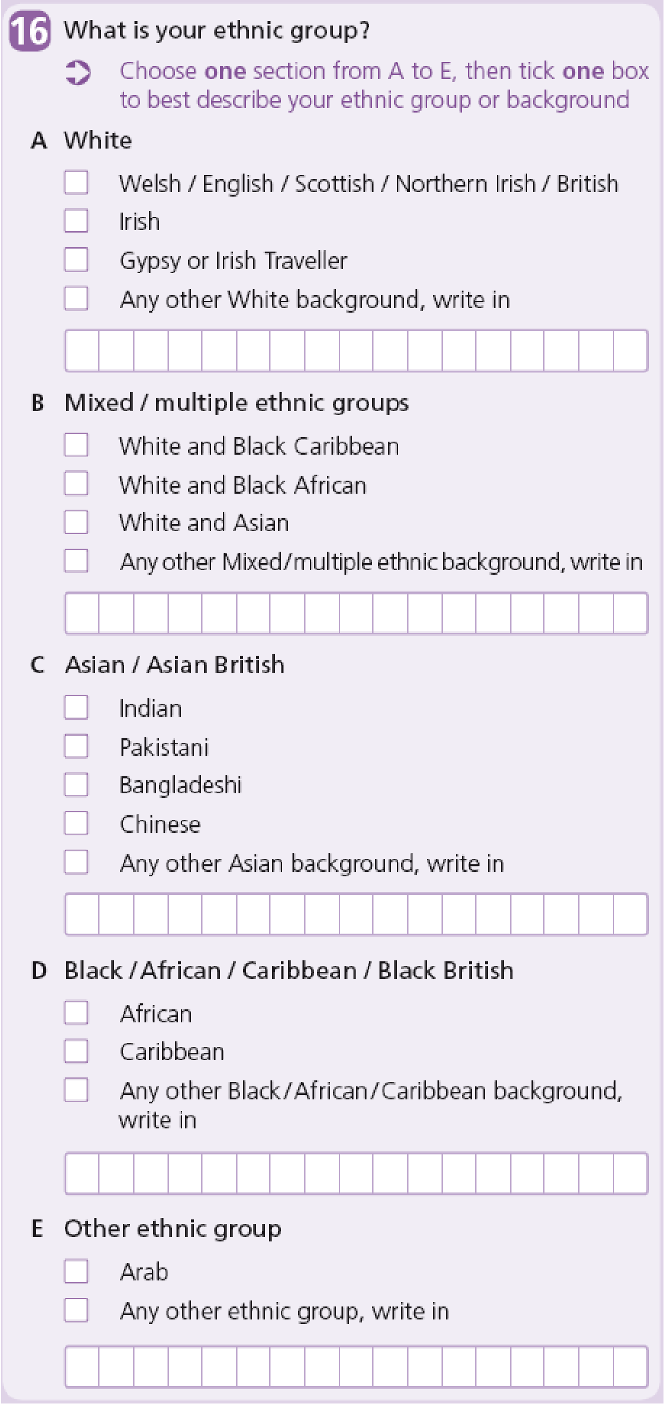
9. Have you received any specific training on hospital discharge or providing care at transitions between settings ?
   Yes No

   If yes, please give brief details ……………………………………………………………….

10. How many years of nursing experience do you have?
    ………………………………………………………….

11. How long have you worked at your current hospital /care home?
    ……………………………………

Ethnicity categories



16 What is your ethnic group?

Choose **one** section from A to E, then tick **one** box to best describe your ethnic group or background

A White

☐ Welsh / English / Scottish / Northern Irish / British
☐ Irish
☐ Gypsy or Irish Traveller
☐ Any other White background, write in

B Mixed / multiple ethnic groups

☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed / multiple ethnic background, write in

C Asian / Asian British

☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background, write in

D Black / African / Caribbean / Black British

☐ African
☐ Caribbean
☐ Any other Black / African / Caribbean background, write in

E Other ethnic group

☐ Arab
☐ Any other ethnic group, write in

Appendix seven: Care home manager information sheet

The role of nurses in optimising the transition from hospitals to care homes for people living with dementia.

Introduction

This project is one of seven at the Doctoral Training Centre (DTC) on Improving Transitions in Dementia Care at the University of Bradford. I have a professional background in mental health nursing with a special interest in dementia care and practice development. My PhD will focus on the transition for nursing home residents living with dementia who are returning to their nursing home following a hospital stay.

Background

The transition between hospital and community care facilities is gaining some academic interest. What we know from these few studies is this transition can be sub-optimal: there are often deficiencies in essential communication with regard to health status and medication; readmission within 30 days are common; inadequate preparation resulting in short notice of transfers increases anxiety for the person, their family and care facilities can find it difficult to plan adequately for the person's needs.

The Project

Study aims, questions and methods

The aim of this study is to identify nurses' perceptions of the care they provide and the facilitators for implementing them for people living with dementia who return to their nursing home following discharge from hospital.

I would like to ask hospital and care home nurses via focus groups or individual interviews:

- What they consider to be the essential elements of care for people living with dementia who return to their nursing home from hospital?
- What they perceive as the nurses' role in providing care?
- What they perceive are the key facilitators and barriers for care?

Focus groups will take place with registered nurses from two hospitals.

Study plan for nursing homes

- Recruit 24 registered nurses from 3- 6 nursing homes who have worked in the nursing home for a minimum of three months.
- Carry out approximately 3-6 focus groups with registered nurses, at their care home. Each group to have between 4-8 registered nurses.

Ethical approval has been obtained for this study and I am now looking for nursing homes that may be interested in taking part. I would like to start recruiting as soon as possible. I anticipate phase one of the study to take place in March /April 2018. It is an opportunity to be involved in developing dementia care practice and as a token of appreciation of care home involvement I am willing to provide staff training/workshop on aspects of dementia care.

I am happy to come and discuss the project with you. For further information, please contact:

Angela Richardson, PhD Student a.richardson13@bradford.ac.uk

Supervised by Professor Murna Downs, Professor Alison Blenkinsopp and Dr. Kathryn Lord.

Appendix eight: Final draft of topic guide

UNIVERSITY of BRADFORD

Optimising the transition for nursing home residents living with dementia who return to their place of care after discharge from hospital.

(Student Project)

Focus Groups and semi-structured interview schedule

Thank you for participating in this focus group/interview. Anything discussed today will be kept confidential, and although we are recording and taking notes, so that we don't miss anything, the data will be anonymised so that individuals will not be identified.

I am interested in hearing about your experiences working with care home residents who have dementia who are in hospital and are transferring back to their care home. I am interested in hearing our views on the essential aspects of care to ensure an effective transition.

If at any point during the discussion you feel you need to stop or leave the room, please do tell me.

Do you have any questions before we start?

1. Tell me about what you currently do when a nursing home resident on your ward/ is ready or almost ready for discharge back to the care home?

(if it doesn't come up ask, how soon before discharge do they involve the care home, who in the family do they involve and how the person is transported back and what is the journey like?)

Care home question

Tell me about what currently happens when one of your residents is in hospital and about what happens when they ready to come back to the nursing home?
(when contacted, notified, type of transport, journey family involvement)

2. What are the main tasks to ensure continuity of care if the patient has complex health issues (e.g. wound care, swallowing issues, catheter care)?

3. What are the main tasks to ensure continuity of care if the person has psychological needs (e.g. anxiety, depression, behaviour changes)?

4. How are these tasks communicated? If it doesn’t come up ask about the release of resident information to the care home nurse, or if the CH nurse has issues in accessing information from hospital

5. Are there any specific considerations you haven’t mentioned because the person is living with dementia?

6. What do you think are the main risks in this transfer?
   - How can these risks be minimised?
   - Who is responsible/accountable for the transfer?

7. What do you think would help nurses to make this transition go well?
   - For example, specific checklists, guidance or documentation?
   - For example, specific training

8. Do you have any examples where this type of transition has gone really well?
   - What happened that made it go well?

9. What do you think are the main barriers to facilitating this transfer of care

Do you have questions or anything else to add to your responses?

This is the end of the focus group/interview. Thank you for your help today. We will now type up the discussion and will send it back to you for checking and comments.

Appendix nine: Draft one of topic guide

UNIVERSITY of BRADFORD

Optimizing the transition for nursing home residents living with dementia who return to their place of care after discharge from hospital

(Student Project)

Focus Groups and semi-structured interview schedule

Thank you for participating in this focus group/interview. Anything discussed today will be kept confidential and although we are recording and taking notes so we don't miss anything, the data will be anonymised so that individuals will not be identified.

The purpose of this focus group / interview is to explore nurses views on what the essential components of care are for people living with dementia who return to their nursing home after discharge from hospital which would ensure an effective transition.

If at any point during the discussion you feel you need to stop or leave the room, please do tell me.

Do you have any questions before we start?

1. If a person living with dementia from a nursing home is in hospital and is due to be returned there what in your view would the nurses working in the hospital need to do provide quality transitional care
    - Who would they need to involve in this process?
    - What would their goal be for involving them?
    - How would they involve them? What communication methods? Any special requirements to consider?
    - How often do you think they would need to involve them for throughout the process?
    - What time shall be allocated to this function?

2. What components of care are required to prepare this person for discharge?
    - Are there any specific considerations because the person is living with dementia?

3. What would you consider to be the main tasks to manage this if they have complex health and or psychosocial needs?

- What do you consider to be important to ensure any medical treatment including medication management is followed up after discharge?

- What do you consider to be important to ensure their psychosocial needs will be followed up after discharge?

4. Who do you think should be responsible for ensuring an effective transfer?
   - What do you think are the main risks?
   - Who in the hospital-based team should the nurse work with to mitigate these risks?
   - Who in the community and/or nursing home should the nurse work with to mitigate these risks?

5. What in your view would the receiving nursing home nurse need to do to ensure the transfer runs smoothly?
   - Who would they need to involve in this process?
   - What would their goal be for involving them?
   - How would they involve them? What communication methods? Any special requirements to consider?

6. Is there anything else required to prepare this person for their return?
   - Are there any specific considerations because the person is living with dementia?

7. What do you think would help nurses to make this transition go smoothly?
   - For example, specific checklists, guidance or documentation?
   - For example, specific training?

8. Do you have any examples where this type of transition has gone really well?
   - What happened that made it go well?
   - Where was this example?
   - Who were the people involved?

9. Do you have questions or anything else to add to your responses?

This is the end of the focus group/interview. Thank you for your help today. We will now type up the discussion and will send it back to you for checking and comments.

Appendix ten: Draft two topic guide

UNIVERSITY of BRADFORD

Optimising the transition for nursing home residents living with dementia who return to their place of care after discharge from hospital.

(Student Project)

Focus Groups and semi-structured interview schedule

Thank you for participating in this focus group/interview. Anything discussed today will be kept confidential, and although we are recording and taking notes, so that we don't miss anything, the data will be anonymised so that individuals will not be identified.

I am interested in hearing about your experiences working with care home residents who have dementia who are in hospital and are transferring back to their care home. I am interested in hearing your views on the essential aspects of care to ensure an effective transition.

If at any point during the discussion you feel you need to stop or leave the room, please do tell me.

Do you have any questions before we start?

1. Tell me about what you currently do when a nursing home resident on your ward/ is ready or almost ready for discharge back to the care home?

   (if it doesn't come up ask, how soon before discharge and how do they involve the care home)

   Care home question

   Tell me about what currently happens when one of your residents is in hospital and about what happens when they ready to come back to the nursing home?
   (when contacted, notified,)

2. What are the main tasks to ensure continuity of care if the patient has complex health issues (e.g. wound care, swallowing issues, catheter care)?

3. What are the main tasks to ensure continuity of care if the person has psychological needs (e.g. anxiety, depression, behaviour changes)?

4. How are these tasks communicated?

5. Are there any specific considerations you haven’t mentioned because the person is living with dementia?

6. What do you think are the main risks in this transfer?
   - How can these risks be minimised?
   - Who is responsible/accountable for the transfer?

7. What do you think would help nurses to make this transition go well?
   - For example, specific checklists, guidance or documentation?
   - For example, specific training

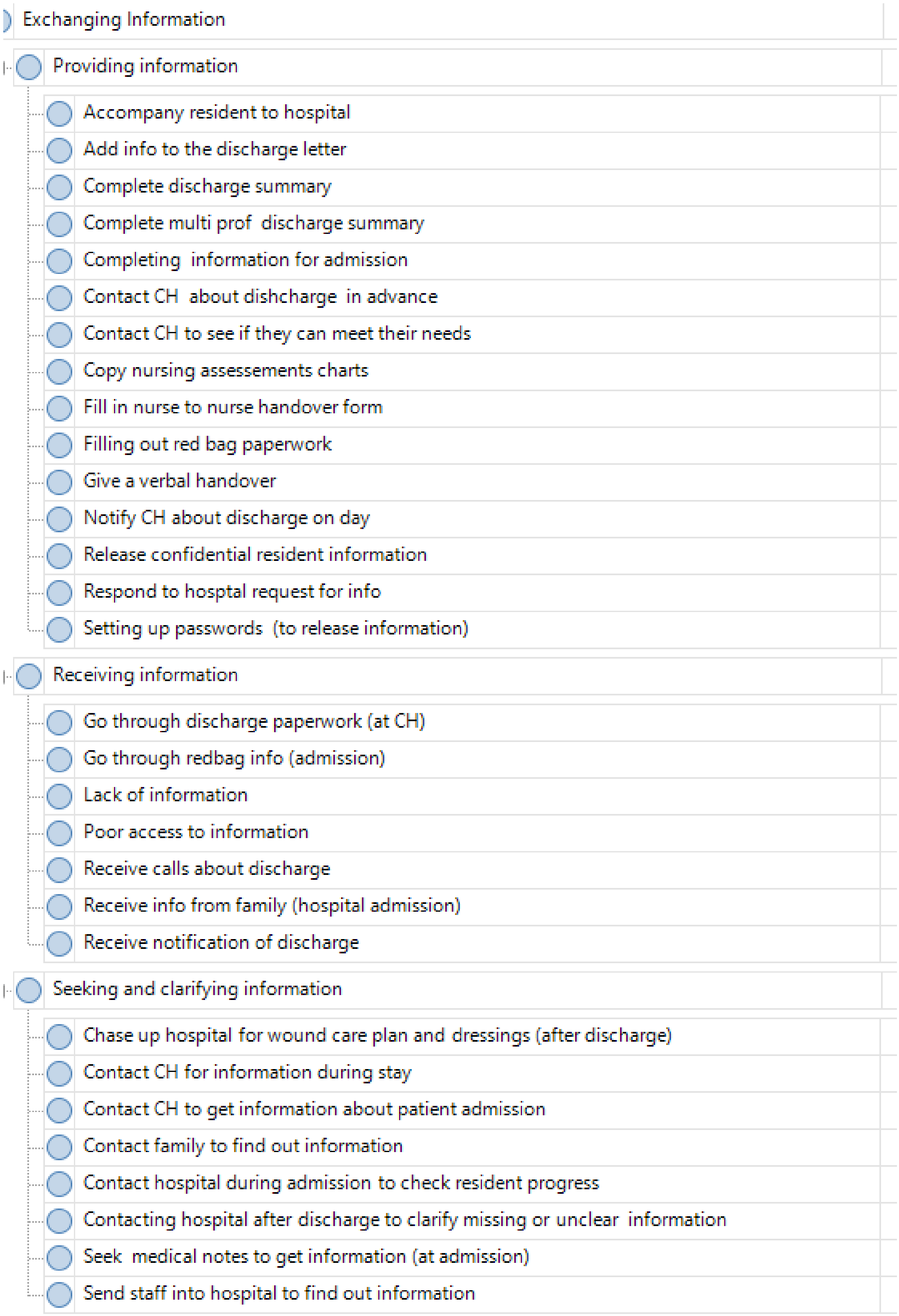
8. Do you have any examples where this type of transition has gone really well?
   - What happened that made it go well?

9. What do you think are the main barriers to facilitating this transfer of care?

Do you have questions or anything else to add to your responses?

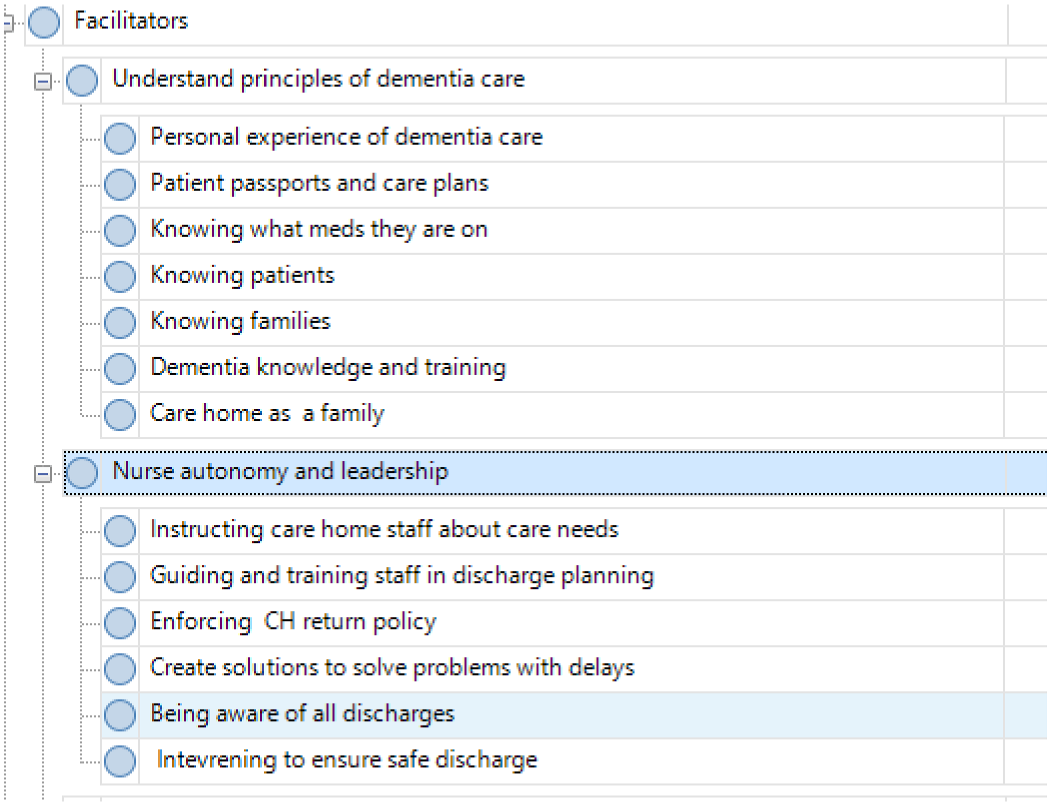
This is the end of the focus group/interview. Thank you for your help today. We will now type up the discussion and will send it back to you for checking and comments.

Appendix eleven: Example of codes

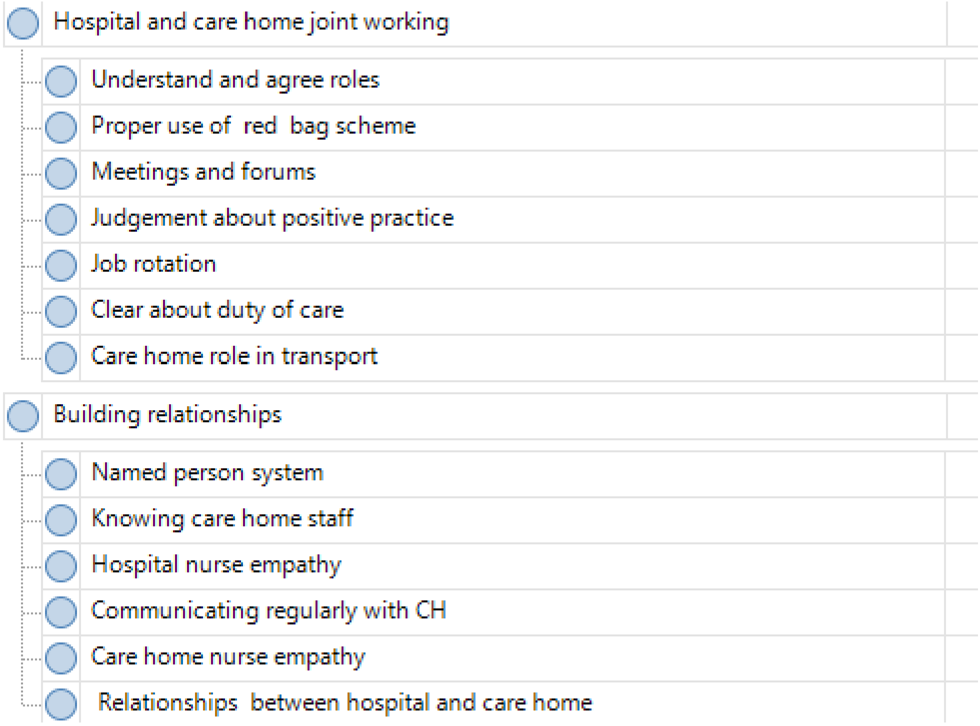


- Exchanging Information
  - Providing information
    - Accompany resident to hospital
    - Add info to the discharge letter
    - Complete discharge summary
    - Complete multi prof discharge summary
    - Completing information for admission
    - Contact CH about dishcharge in advance
    - Contact CH to see if they can meet their needs
    - Copy nursing assessements charts
    - Fill in nurse to nurse handover form
    - Filling out red bag paperwork
    - Give a verbal handover
    - Notify CH about discharge on day
    - Release confidential resident information
    - Respond to hosptal request for info
    - Setting up passwords (to release information)
  - Receiving information
    - Go through discharge paperwork (at CH)
    - Go through redbag info (admission)
    - Lack of information
    - Poor access to information
    - Receive calls about discharge
    - Receive info from family (hospital admission)
    - Receive notification of discharge
  - Seeking and clarifying information
    - Chase up hospital for wound care plan and dressings (after discharge)
    - Contact CH for information during stay
    - Contact CH to get information about patient admission
    - Contact family to find out information
    - Contact hospital during admission to check resident progress
    - Contacting hospital after discharge to clarify missing or unclear information
    - Seek medical notes to get information (at admission)
    - Send staff into hospital to find out information

Appendix twelve: Example themes and codes



- Facilitators
  - Understand principles of dementia care
    - Personal experience of dementia care
    - Patient passports and care plans
    - Knowing what meds they are on
    - Knowing patients
    - Knowing families
    - Dementia knowledge and training
    - Care home as a family
  - Nurse autonomy and leadership
    - Instructing care home staff about care needs
    - Guiding and training staff in discharge planning
    - Enforcing CH return policy
    - Create solutions to solve problems with delays
    - Being aware of all discharges
    - Intevrening to ensure safe discharge



- Hospital and care home joint working
  - Understand and agree roles
  - Proper use of red bag scheme
  - Meetings and forums
  - Judgement about positive practice
  - Job rotation
  - Clear about duty of care
  - Care home role in transport
- Building relationships
  - Named person system
  - Knowing care home staff
  - Hospital nurse empathy
  - Communicating regularly with CH
  - Care home nurse empathy
  - Relationships between hospital and care home

Appendix thirteen: List of presentations

List of presentations most recent first

Conference and symposium papers presented

1. Richardson, A, Downs, M, Blenkinsopp, A. Lord, K. *Optimising nursing care of people living with dementia who return to their nursing home from hospita*l, Royal College of Nursing International research conference, 5th September 2019, Sheffield.

2. Hill, S., Richardson, A., Blenkinsopp, A, Downs, M *Transitions of care between hospitals and care home settings for people living with dementia.* British Society of Gerontology Symposium, 10-12 July 2019, Liverpool.

3. Richardson, A, Downs, M, Blenkinsopp, A. Lord, *UK nurses' views on their role in hospital to care home transitions for people living with dementia*. Gerontology Society of America (GSA) Symposium Nov 14-18, 2018. Boston, USA

Poster presentations

1. Richardson, A., The role of nurses in optimising the transition from hospitals to nursing homes for people living with dementia. 25 February 2019, University of Bradford Postgraduate Students Research Presentation Day.

2. Richardson, A., The role of nurses in optimising the transition from hospitals to nursing homes for people living with dementia. 22 October 2018, University of Bradford Presentation to DTC Stakeholder panel.

3. Richardson, A, Downs, M, Blenkinsopp, A. Lord, K. Optimising the transitions from hospitals to care homes for people living with dementia. 19th May 2017, Alzheimer's Society Research Conference, Covent Garden, London.

Presentation to lay and professional audience

1. Angela Richardson, Nurse preparedness for dementia care for hospital to care home transitions, November 2018, Penn State University, USA

2. Angela Richardson, *Optimising the transition from hospitals to nursing homes*, 8th May 2019, Research event on Delivering a High-Quality Service in Dementia Care organised by NHS Bradford District Clinical Commissioning Group. Leeds.

Presentations to Stakeholder advisory groups

- Progress to date - Students presented their progress to the Carer Reference Panel, 17 February,2020
- Progress to date - Students presented their progress to the Carer Reference Panel, 17, July 2019
- Progress to date - Students presented their progress to the Stakeholders Advisory Group, 15, May 2019

- Progress to date - Students presented their progress to the Carer Reference Panel, 6, February 2019
- DTC Projects- Presentation on Dementia Action week, Skipton Building Society, 24, May 2018
- DTC transitions in dementia care, Working Together To Beat Dementia event Dementia PPI event. 14th March 2018, York.