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Person-centred hydration care for older people living with dementia in acute hospital wards: A case study

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Glossary of acronyms

| | |
|--------------|---|
| ADLs | Activities of daily living |
| CQC | Care Quality Commission |
| CQUIN | Commissioning for Quality and Innovation |
| HCA | Healthcare assistant |
| HCP | Healthcare professional |
| JBI | Joanna Briggs Institute |
| MDT | Multi-disciplinary team |
| NHS | National Health Service |
| NHSG | Nutrition and Hydration Strategy Group |
| NOK | Next of kin |
| OATN | Older adult team nurse |
| OAT | Older adult team |
| Obs | Observation |
| OPLWD | Older person / people living with dementia (over the age of 65) |
| OT | Occupational therapist |
| PCC | Person-centred care |
| PCNF | Person-centred nursing framework |
| PCPF | Person-centred practice framework |
| PLWD | Person / people living with dementia (any age) |
| SN | Staff nurse |
| StN | Student nurse |
| WL | Ward leaders |

Abstract

Purpose: Admission to acute hospital can be detrimental to the physical and psychological health of older people living with dementia (OPLWD). Evidence demonstrates that currently, person-centred dementia care within hospitals remains in flux and staff struggle to meet the biopsychosocial needs of people living with dementia. This thesis uses the concept of person-centred care to explore how oral hydration care is delivered for older people living with dementia admitted to an acute hospital, a topic infrequently explored in research.

Methods: A multiple case study was conducted across three wards within one acute hospital. Contextual hospital data were collected through five interviews with senior staff and policy documentary analysis. Ward-level data collection comprised 132 hours of direct observation with 13 OPLWD and staff providing care, 37 interviews with staff, people living with dementia and their relatives, and documentary analysis of 38 clinical patient-records. Data were analysed using framework approach.

Findings: Organisationally, oral hydration care for OPLWD is not prioritised; it is not a topic of national importance with required reporting.

At ward level, oral hydration care is not prioritised by healthcare staff who are influenced by organisational priorities. Staff hydration roles are disjointed, and drink delivery outsourced. The approach to facilitating hydration care between and within ward staff, OPLWD and their relatives is insufficient to consistently provide person-centred hydration care. By utilising: Communication, Action, Resources and Environmental considerations, encompassing staff's approach and the needs of older people living with dementia and their relatives, person-centred oral hydration CARE could be facilitated.

Conclusion: This thesis brings the concepts of person-centred care and hydration care for OPLWD admitted to an acute hospital together for the first time, demonstrating that person-centred hydration care is complex and not currently prioritised. Acute hospitals should improve the person-centred delivery of oral hydration care for OPLWD, to improve their health and wellbeing.

1 Background

1.1 Introduction

“Thousands have lived without love, not one without water” – W. H. Auden

A life without love or relationships is difficult to imagine but life without water, impossible. Hydration is essential for human life. This PhD thesis explores the connectedness of hydration, relationships, and interactions when an older person living with dementia (OPLWD) is admitted to an acute hospital ward and requires assistance with fundamental oral hydration care and human interactions.

This is the first chapter of the thesis and sets the scene for the study on hydration care for OPLWD when they are admitted to acute hospitals. The chapter starts by introducing the topic of hydration, positioning it as complex, biopsychosocial aspect of care. My positioning as a researcher will be discussed in 1.3, followed by a discussion of how this topic was chosen in 1.4. Dementia is then introduced, followed by a discussion about dementia care within hospitals in sections 1.5 and 1.6, In section 1.7 I examine the relevant policy and papers from the United Kingdom about dementia care within acute hospitals. The chapter concludes with an overall summary of the thesis.

1.2 Importance of hydration

When contemplating hydration, healthcare workers may instantaneously consider associated biological and physiological aspects. In nursing textbooks, hydration is described as a ‘status’ linked to the homeostatic state of the body; its ability to maintain a constant internal environment, connected to the intake and excretion of

fluids (Dougherty *et al.*, 2015). Hydration is physiologically vital for life: maintaining body temperature, delivery of nutrients and gases to cells and the removal of waste, affecting blood volume and cellular function (Scott, 2010). For these reasons hydration is placed within “nutrition, hydration, bladder and bowel care, physical handling and making sure those receiving care are kept in clean and hygienic conditions” as fundamental care in The Code for Nurses, Midwives and Nursing Associates (NMC, 2018, p. 7). Delivering fundamentals of care is sometimes considered ‘basic’ or ‘common sense’ (Feo *et al.*, 2019), however, amongst nursing scholars there is growing evidence that the fundamentals of care, reliant on interactions, are complex and under-researched (Ball *et al.*, 2016; Feo *et al.*, 2019; Kitson *et al.*, 2014). This emerging approach recognises fundamentals of care are comprised of psychosocial, relational and physical care (Feo *et al.*, 2018a). Hydration is captured within the category of *physical* fundamental care but in practice there is a relationship between the relational, psychosocial and physical fundamentals of care, which is not always represented in the literature (Feo *et al.*, 2018b). There is worldwide evidence that fundamental care, including hydration, within acute hospitals, may not be being delivered effectively or in a patient-centred way, prompting a collaboration of nursing researchers to focus on addressing this (Kitson *et al.*, 2013, 2014). Therefore, this research topic has current and international importance. The focus of this thesis is oral hydration; the word ‘hydration’ will be used throughout to mean ‘oral hydration’. Other forms of hydration will be referred to with the appropriate prefix, for example, ‘intravenous hydration’.

Hydration is not only fundamental because it is physiologically important; hydration, drinking fluids, is part of people’s daily social lives. Consumption of food and drinks have rituals, across the world and throughout history. Our Bronze Age ancestors

considered their drinking vessels so important they buried their dead with cups alongside weapons and gold (Johnson, 2002). Modern-day archaeologists define whole periods and cultures from these finds: the 'corded ware communities' were driven out by 'the beaker people.' (Fitzpatrick, 2013; Sjögren *et al.*, 2016). Entire nations can be stereotyped by their tippable of choice; tourists may seek 'English Breakfast' tea in London or observe a Japanese tea ceremony whilst in Tokyo. It is not only because drinking provides sustenance that it occupies a central position in everyday life: the psychosocial aspects of drinking, through social bonding and impact on mood, also contribute to the centrality of drinking (Ratcliffe *et al.*, 2019). The act of drinking provides an opportunity for social interactions to take place which are familiar to all people. What, when, how and with whom we drink forms part of our identity.

Some people are less able to access hydration than others, perhaps due to environmental barriers such as water supply (Wutich and Ragsdale, 2008). A person's functional abilities may preclude their ability to acquire necessary drinks. There are groups of people considered to be high risk for maintaining sufficient hydration: older people, frail, very young or those with significant disabilities (Holroyd, 2020). OPLWD fall within this group.

1.2.1 Dehydration

Older adults have specific risks which make them susceptible to low fluid intake and a serious consequence of not addressing hydration is dehydration. Older adults are at increased risk of dehydration; fluid reserves are smaller due to reduced muscle mass, additionally kidney function is reduced, affecting fluid retention (Edmonds *et al.*, 2021; Hooper *et al.*, 2014). The thirst response reduces with age so older adults

are less likely to drink when their body needs to hydrate (Mentes, 2006a). Dehydration has associated morbidity and mortality risks for older people including urinary tract infections, constipation, heat stress and pressure ulcers (Hooper *et al.*, 2015), while electrolyte imbalances can cause health complications such as delirium, disability, lengthened hospital admissions, bradyarrhythmia, transient ischemic attacks, kidney failure, oral health, frailty or mortality (Bunn *et al.*, 2015; Cook, 2017; Edmonds *et al.*, 2021; Manz and Wentz, 2005). A potential combination of immobility, confusion, dementia, hypertension or renal disease results in older adults being sensitive to fluid and electrolyte imbalances and dehydration (Hodgkinson *et al.*, 2003). In addition to the risk factors of older adults, OPLWD may have communication problems or forget to drink (Archibald, 2006).

In this thesis there is no definite target provided for the total fluid an older person should drink in a day. Cook *et al.*, (2019b), in their review of hydration in care homes, describe the recommendation for the amount of fluid an older people should drink as an area of controversy and highlight several possible recommendations. Although guidelines exist, such as 8 x 8oz glasses of water per day or 1600mls for women and 2000mls for men, recommendations change based on factors including but not limited to age, gender, physical activity (British Dietetic Association, 2017; Cook *et al.*, 2019b).

Several literature reviews exploring hydration and related issues for older people in care settings have been published during this PhD, further supporting that this is a topic of importance for healthcare researchers and scholars (Hooper *et al.*, 2016; Wilson and Dewing, 2020). The existing reviews (see appendix one for a table of these reviews) have focussed on assessing dehydration for people at risk of low

intake; the optimum intake, ways to assess dehydration and assess risk of low intake- which remain contested (Abdelhamid *et al.*, 2016; Bunn *et al.*, 2015, 2016; Cook *et al.*, 2019b; Hodgkinson *et al.*, 2003; Oates and Price, 2017; Wilson and Dewing, 2020).

Most of the reviews focussed on interventions to increase fluid intake for older people (Abdelhamid *et al.*, 2016; Bunn *et al.*, 2015, 2016; Cook *et al.*, 2019b; Oates and Price, 2017). The reviews which assessed interventions for increasing nutritional and fluid intake for people with dementia found most studies related to nutrition rather than hydration (Abdelhamid *et al.*, 2016; Bunn *et al.*, 2016). The reviews mostly provide evidence for older people in long-term care settings; even where hospital settings were incorporated into the review inclusion criteria, most of the studies identified in the search related to long-term care settings (Abdelhamid *et al.*, 2016; Oates and Price, 2017; Wilson and Dewing, 2020). Whilst the reviews demonstrate there are potential ways to increase the oral intake of older people in hospitals and long-term care settings, there were limitations in the knowledge base. Two reviews indicated that studies had not approached the interventions considering person-centred care (PCC) and that this would be of benefit to further investigations (Bunn *et al.*, 2015; Cook *et al.*, 2019b). The reviews demonstrate there are gaps in the knowledge base relating to evidence about hydration care for OPLWD in acute hospitals. The existing literature reviews did not provide any evidence into the current practice of hydration care for older adults in hospitals or any of the contextual issues relating to hydration care.

1.2.2 Summary of hydration

This section presented how hydration and drinking can be viewed from a biopsychosocial perspective; it is important physiologically to maintain health and the functions of the body and it is linked to people's social connections with the world. Rationale was provided about why older people, particularly OPLWD, are at risk of not maintaining hydration, making this a particularly important area to consider for the health and wellbeing of this population. Recent literature reviews on related topics - dehydration, hydration interventions and optimal intake - were introduced, justifying this as a contemporary issue. However, the focus of this thesis is hydration care, not dehydration, which I have demonstrated other research has focussed on. A focus on hydration for older people is not only important because of the risk factors they have around becoming dehydrated but also because hydration has important associated psychological and social elements. Within care settings, particularly acute hospitals, there is uncertainty about the optimal ways to promote hydration for older people and this will be explored further through chapter two.

1.3 Positioning myself as a researcher

To position myself as a researcher, it is important to make clear that my first healthcare role was as a healthcare assistant in a nursing home for people living with dementia. During that role I was taught the concept of person-centred care (explored through chapter three), which became integral to my view of dementia. I am now a registered mental health nurse working clinically, with previous dementia research experience.

During my mental health nursing degree education (2009 – 2012) there were huge waves of discomfort felt across healthcare services, particularly care for older people in hospitals. This was due to the findings of the Independent Inquiry into care at Mid Staffordshire NHS Foundation Trust that failures in ‘basic nursing care’ had led to the injury or death of patients within that Trust (Francis, 2010). Evidence was given by families that their relatives had experienced distressingly absent care in areas such as continence, nutrition, hydration, pressure area and personal care, leading, in some cases, to deaths. It is with that backdrop that my nursing education took place, firmly situating the importance of fundamental care as an essential component of nursing.

Through my various roles in healthcare, I have been in many settings where I have interacted with OPLWD. I have enjoyed hearing stories while pouring a choice of lemon or blackcurrant squash. I have had difficult conversations made more personal by sharing a drink. I have felt the private connection of holding a cup to a person’s lips when they are no longer able to do so themselves. I have experienced the emotional pain of being in a care environment and seeing busy staff struggling to find the time to provide oral fluids as part of fundamental care – sometimes, I have been that struggling nurse. I come to this topic with a view that interactions and fundamental hydration care are both essential elements of care delivery and that everyone involved in healthcare has a duty to get these aspects of fundamental care right.

These pre-existing roles shape my view of the topic as described and my position as a researcher when observing care as a method of data collection, further discussed in 4.8.3. Although I am an insider to nursing practice, while undertaking

this doctoral research I was an outsider and visitor to acute hospital wards in my role as a researcher, who held a nursing registration.

1.4 Why choose to investigate hydration?

This study is funded by a scholarship which had the criteria to conduct research on a topic which would improve the care of OPLWD in acute hospitals. The opportunity to identify a topic came at a time I had been collecting research data, through interviewing staff who were caring for distressed people living with dementia (PLWD) admitted to acute hospitals (Sampson *et al.*, 2019). The staff acknowledged the challenges of their role, explaining they did not consistently have the time to interact with PLWD. On the occasions when I left these interviews and saw drinks out of reach of PLWD and staff occupied with other tasks, distanced from the PLWD, I became curious as to how fundamental hydration care was conducted for PLWD, especially when staff reported struggling to interact.

Additionally, the priorities of PLWD and their relatives aligned with my existing interest. The James Lind Alliance in association with PLWD and their relatives developed ten dementia research priorities; two areas were: ways to care for PLWD in acute hospitals, and finding ways to support PLWD with eating and drinking (Alzheimer's Society, 2013). On reading these research priorities my curiosity about this topic was solidified into a drive to investigate it. Dementia is now discussed further.

1.5 Dementia

People living with dementia (PLWD) are unique, through their life histories and circumstances and how they experience dementia. Dementia is a condition caused by chemical and structural changes in the brain, an umbrella term for a set of cognitive and behavioural symptoms, which are progressive (Prince *et al.*, 2007). The cognitive symptoms can include problems with memory, concentrating, planning, language, visuospatial skills or orientation; additionally, a person can experience changes to their mood such as becoming frustrated, anxious or easily upset (Alzheimer's Society, 2015). Many diseases can cause dementia, most commonly: Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia (National Institute for Health and Care Excellence, 2018). These symptoms can be life changing and as a result PLWD may require care and support with some or all aspects of their life.

The term, dementia, may be viewed as having negative associations; the etymology comes from the Latin words 'de' (out of) and 'mens' (mind) (Livingston *et al.*, 2017). The fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has changed the classification of dementia to neurocognitive disorders (American Psychiatric Association, 2013). Whilst the DSM-5 is relevant to the diagnostic process it also opens a space to consider the language ascribed to a dementia diagnosis (Sachdev *et al.*, 2015). The word dementia remains the most common term used within practice and literature within the UK and Europe, where this research is taking place. There can be stigma attached to aspects of dementia and the language used to describe the experience of a PLWD may entrench stigmatising views (Swaffer, 2014). To view the use of the term 'dementia' as the reason for stigma may be too reductive. To overcome the risk of

stigmatisation, words used to portray the experience of the PLWD should be inclusive, non-judgemental and support the whole-person positively rather than using negative or discriminatory language (Swaffer, 2014). I have made the decision to use the term dementia within this thesis to describe the symptoms detailed above. When referring to an older person who is living with a diagnosis of dementia, I will use the wording an older person living with dementia (OPLWD), which is in keeping with positive language guides (Alzheimer's Society, 2018; DEEP, 2014). When referencing literature that has not specified the age of the person living with dementia, I will use the term person living with dementia (PLWD). I use abbreviations for practical reasons, due to the thesis word constraint.

Although many PLWD lead fulfilling lives, the symptoms can result in people finding aspects of daily living challenging, meaning they require support from others, particularly as the disease progresses. This research focusses on older adults, defined chronologically using the age 65 years and over. The use of chronological age to define an older adult is debateable, as this does not indicate level of functioning or overall health over time or across different global locations (Singh and Bajorek, 2014). The definition of an older adult as 65+ is in keeping with many recognised resources, so will be used in this research (Age UK, 2019; Office for National Statistics, 2019). Older people can also experience stigma, based on age discrimination, which places OPLWD at risk of experiencing a double discrimination-based on age and dementia diagnosis (Milne, 2010). Anyone can develop dementia, although diagnosis becomes more prevalent in older people; one in 14 people over the age of 65 have dementia and one in six people over 80 (NHS, 2020). The number of PLWD is increasing because people are living longer. However, dementia is not a normal part of ageing.

Dementia is a local and global issue, considered “the greatest global challenge for health and social care in the 21st century” (Livingston *et al.*, 2017, p. 2673). Worldwide, there are 50 million people living with dementia and 10 million new cases every year (World Health Organisation, 2020). In 2019 there were an estimated 885,000 older people with dementia in the UK (Wittenberg *et al.*, 2019). It is estimated this will rise to one million by 2025 (Prince *et al.*, 2007).

Earlier in this section a definition of dementia was provided which discussed the symptoms associated with dementia. That is one way of viewing dementia but taken alone can lead to dementia being viewed in biomedical terms only, which neglects a holistic (biopsychosocial) understanding (Bond, 1992). Dementia can also be understood using psychological and sociological perspectives (Cantley, 2001). The different sociological perspectives which contribute to the understanding of dementia come from sociological explorations of illness. The social model of disability explores how society impacts and potentially oppresses disabled people, challenging the view that the problem lies within the individual and reflecting the issue at societal-level (Oliver, 1986, 1990). Applying the social model of disability to dementia care allows an exploration about whether services are set up to accommodate PLWD, although the model may not currently be at a place to fully involve PLWD (Gilliard *et al.*, 2005). Another sociological perspective involving society is political economy which explores the influence of politics and economy. For OPLWD this relates to their position in society and the potential for ageism, including a lack of resource allocation and the impact on service provision (Bond, 2001; Townsend, 1981).

The most prominent psychological perspective is compiled through the work of Tom Kitwood. His seminal work “Dementia Reconsidered: The Person Comes First” (Kitwood, 1997) presents a justification for considering dementia through a social psychological perspective, also considering biological aspects, leading to a view of dementia through person-centred care (PCC), which has a biopsychosocial approach (Brooker and Latham, 2016, p. 19). Particularly as there is no cure for dementia, providing good quality, biopsychosocial care which improves quality of life, health and wellbeing for PLWD is essential (Livingston *et al.*, 2017). PCC is seen as the optimal approach to care, underpinning good practice for delivery of dementia care in all settings (National Institute for Health and Care Excellence [NICE], 2018).

These NICE guidelines define the underpinning aspects of PCC as asserting:

- *“The human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers.*
- *The individuality of people living with dementia, and how their personality and life experiences influence their response to dementia.*
- *The importance of the person's perspective.*
- *The importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.”* (NICE, 2018, p. 10)

This definition is based on the ‘VIPS Framework’ of PCC, developed by Brooker and Latham (2015) which stands for Valuing people, Individual perspectives, Personal perspectives and Social environment.

The next section explores what happens when an OPLWD is admitted to an acute hospital, demonstrating evidence that optimum care is not always provided,

therefore it is an important area for ongoing research with potential for improvements in care to be made.

1.6 Dementia care within hospitals

Reports, policy and research have demonstrated that when a PLWD is admitted to an acute hospital it can be harmful to them, by having a detrimental impact on their health and wellbeing (Alzheimer's Society, 2016a; Care Quality Commission [CQC], 2014; Cowdell, 2006; Francis, 2013; Gladman and Porock, 2012). This is concerning, particularly as large numbers of PLWD are admitted to hospitals, usually for medical reasons, not due to dementia (Alzheimer's Society, 2016a). The CQC (2014) estimates that a quarter of all people aged over 65 years admitted to UK acute hospitals are living with dementia. Goldberg *et al.* (2012) found over half of people aged 75+ admitted to acute hospitals had a cognitive impairment. Over-65s are frequent users of hospitals; approximately 43% of people admitted to UK hospitals non-electively are in this cohort (Oliver *et al.*, 2014). Over 65s also stay in hospital longer than other age groups and account for 80% of National Health Service (NHS) hospital admissions lasting more than two weeks (Poteliakhoff and Thompson, 2011).

In a meta-analysis of hospital admissions for PLWD, Shepherd *et al.* (2019) found that having dementia increased the risk of hospitalisation compared to those without dementia. They also found that older age in those with dementia was associated with a higher risk of admission, and some moderate evidence that having physical comorbidities, a lower functional level or taking seven or more medications were associated with being admitted to hospital. These findings demonstrate when a

PLWD is admitted to hospital, they are likely to have multiple physical health and functional needs which require care and support from hospital staff.

Evidence suggests hospital staff have difficulty providing the physical and relational care required to consistently meet the biopsychosocial needs of the PLWD in acute hospital, contributing to PLWD having negative experiences of hospital (Røsvik and Rokstad, 2020). PLWD experience a multitude of adverse physical consequences when admitted to hospitals including long stays, excessive falls (Walker *et al.*, 2005), functional decline (Pedone *et al.*, 2005) and delirium (Avelino-Silva *et al.*, 2017) or develop malnutrition and/or dehydration (Fogg *et al.*, 2018). These adverse consequences can have social and psychological risks, including discharge to a nursing or care home (Fogg *et al.*, 2018), or the PLWD can experience loss of dignity, as well as the admission being frightening (Alzheimer's Society, 2016a). These adversities can ultimately lead to death (Fogg *et al.*, 2018). These consequences impact PLWD and their relatives and are associated with increased cost of care (Alzheimer's Society, 2016a). The causes for these adverse consequences are complex and interlinked with the outcomes and linked to fundamental care; they include: malnutrition (O'Shea *et al.*, 2017), dehydration (El-Sharkawy *et al.*, 2015), falls (Lang *et al.*, 2006), polypharmacy (Prudent *et al.*, 2008), and environmental factors, such as room changes, isolation and lack of orientation (McCusker *et al.*, 2001). The current situation for PLWD who are admitted to acute hospitals requires improvement and delivery of fundamental care is an area where improvements can be made.

The need and drive to improve dementia care within acute hospitals is reflected in a range of reports and policies within the UK which will be discussed in the next

section along with their key findings and recommendations. These have been selected as they provide a contemporaneous overview of the national perspective for the UK, where this research takes place.

1.7 Dementia policy, strategies and reports

UK policy, strategies and reports demonstrate that there is a nationwide interest in improving dementia care within hospitals from government, professional bodies, charity sector and regulators. This is captured in the Prime Minister's Challenge on Dementia (Department of Health [DH], 2012) which set aims for the UK to become a world leader in dementia care and research. This included finance to achieve its aims, providing further incentive for organisations. Table 1.1 summarises the relevant policies, strategies and reports released by the government, charities, action groups, professional colleges and regulators which have contributed to the knowledge about and drive to improve dementia care within hospitals. Table 1.1 also indicates if the reports have advocated PCC, as well as any discussion relating to fundamental hydration care. If a report has been superseded, only the most recent version is included.

The policy, strategies and reports support the argument that there is a need to further understand and work towards improving the care PLWD experience when they are admitted to acute hospital wards. Most documents advocate the use of PCC, which will be discussed further in chapter three. Most documents have some limited discussion about hydration, supporting the view that this fundamental care need has relevance to the care of PLWD in hospital. However, these documents do not explore hydration care in depth.

Table 1.1: Policies, reports and strategies relevant to dementia care in acute hospitals from the UK in the past 10 years

| Document reference and title | Objective of document | Key points about hospital care for PLWD | Does it advocate PCC? | Are there any points related to fundamental hydration care? |
|---|---|---|---|--|
| Prime Minister's Challenge on Dementia (DH, 2012) | Building on the work of the National Dementia Strategy (DH, 2009), it sets out aims to make the UK a world leader in dementia care and research. It has three areas of focus: improving health and social care, creating dementia-friendly communities, and improving research. | Financial rewards are offered to hospitals in the form of a Dementia Commissioning for Quality and Innovation (CQUIN) when hospitals offer a dementia risk assessment to patients over 75. The CQUIN was also scheduled to include the quality of dementia care and delivering support for relatives. | Uses the term 'personalised care.' | No. |
| Dementia: Commitment to the care of people with dementia in hospital settings (Royal College of Nursing, 2013) | This is a resource made by the Royal College of Nursing (RCN) in collaboration with the DH. It sets out five principles for dementia care, communicated using the acronym SPACE. | To communicate the principles of good dementia care in hospital, the acronym SPACE – supporting good dementia care - stands for: Staff who are skilled and have time to care. Partnership working with relatives. Assessment and early identification. Care that is individualised. Environments that are dementia friendly. | Yes, uses the VIPs Framework (Brooker and Latham, 2016) | Yes, one of the considerations for training is to develop and understand the skills to enhance the quality of life for PLWD, through a range of topics including nutrition and hydration. Reports that nutrition and hydration have been recognised as major issues for older people in hospital (Age UK, 2010) |

| Document reference and title | Objective of document | Key points about hospital care for PLWD | Does it advocate PCC? | Are there any points related to fundamental hydration care? |
|--|--|---|--|---|
| Mending cracks in the pathway (Care Quality Commission [CQC], 2014) | The report presents the findings of a thematic review of the care of PLWD as they transition between care homes and acute hospitals. The report aims to highlight the variability in care, as well as highlight good care. | The CQC sets out to make a commitment to improving their inspections of dementia care by appointing a new specialist adviser, training inspectors about good dementia care and adding a section to hospital inspection reports that focusses on how the hospital cares for PLWD. The report presents data comparing care homes and hospitals in areas including assessment of care needs, providers working together, involvement, planning and delivery of care, staffing and monitoring the quality of care. The report states that across more than 90% of care homes and hospitals they found aspects of variable or poor care. | Yes, a person-centred approach is discussed under the section on assessment process. It connects an understanding of the person's life as part of a good assessment process. | Dehydration is discussed in the section about urinary tract infections (UTIs) and preventative admission to hospitals from care homes. It is said that for people with dementia living in care homes there is a risk of dehydration which can result in hospital admissions. It reports when staff continually prompted people to drink throughout the day this supported good care and reduced the risk of UTIs. |
| Prime Minister's Challenge on Dementia 2020 (DH, 2015) | Builds on the work of the Prime Ministers Challenge on Dementia (DH, 2012). It sets out aims to make England the best country in the world for dementia care and support and the UK the best place to undertake dementia research. | It draws on the CQC (2014) report to recommend that improvements should be made in assessments of the person's needs, improving poor care that does not meet a person's psychological and social needs and improving variable care where there is a lack of understanding and knowledge about dementia by staff. The report sets out the aim that by 2020 all hospitals and care homes will meet the agreed criteria to be a dementia-friendly health and care setting, including, that when a person is receiving end of life care in hospital, relatives are offered the right to stay. It reports that it is using the CQUIN to improve identification of dementia in hospitals, and the appointment of a CQC national specialist adviser for dementia to improve inspection of dementia care in hospitals. It states there will be £50 million invested in creating dementia friendly environments in hospitals (and care homes). | Uses the terms 'personalised care' and 'compassionate care.' Uses the term PCC when discussing end of life care. Uses the term person-centred when discussing reducing inappropriate anti-psychotic prescribing. | Yes, it states that PLWD in care homes are more likely to be admitted to hospitals with avoidable conditions including dehydration, infections and pressure ulcers than those without dementia. It discusses understanding that behaviours that challenge have multiple causes including poor hydration. It states that a better understanding of this can reduce admissions to hospitals and care homes and reduce unnecessary anti-psychotic prescribing. |

| Document reference and title | Objective of document | Key points about hospital care for PLWD | Does it advocate PCC? | Are there any points related to fundamental hydration care? |
|---|---|---|---------------------------|--|
| <p>Fix Dementia Care: Hospitals (Alzheimer's Society, 2016a)</p> | <p>To start a public campaign to improve hospital care for PLWD, with recommendations for the NHS and health regulators.</p> <p>It presents findings from freedom of information requests from hospitals in England, an analysis of government and NHS data and a survey from a sample of 570 self-selected relatives affected by dementia.</p> | <p>The document presents statistics about the PLWD when in hospital: not being treated with dignity or understanding (60%), the hospital being frightening for the person (92%), the person becoming more confused in hospital (90%). The number of PLWD who fell in hospital the prior year (n= 6834), the number of PLWD discharged between 11pm and 6am (n= 4926). Other information is that the length of stay is twice as long for PLWD as other people aged over 65. The survey reported only 2% of hospital staff understood the needs of PLWD. 25% of hospital beds were occupied by PLWD, in 2013/2014. £264.2m was wasted on poor dementia care in hospitals.</p> <p>The document makes recommendations about transparency, expressing the view that hospitals should publish annual statements on dementia care, monitor the statement usage as part of the risk assessment framework, and act on inadequate care. The CQC should appoint a specialist dementia adviser and include dementia care indicators as part of regulation in hospitals.</p> | <p>Yes, advocates PCC</p> | <p>Yes. The report advocates using the Alzheimer's Society document, <i>This is me</i>, to gather information about a person's preferences and needs. They report it can help overcome problems with communication and prevent dehydration.</p> <p>The report presents case studies based on the findings. These included issues related to drinking, including staff not monitoring eating and drinking leading to weight loss, and not having the right drinks available in A&E.</p> |

| Document reference and title | Objective of document | Key points about hospital care for PLWD | Does it advocate PCC? | Are there any points related to fundamental hydration care? |
|---|---|---|---|---|
| Dementia-friendly hospital charter: Revised 2018 (Dementia Action Alliance, 2018) | Aims to be a call to action for hospitals to become dementia-friendly. The charter espouses the principles that a dementia-friendly hospital should achieve, including a self-assessment for hospitals and recommended actions. | The principles include: staff providing care are appropriately trained and knowledgeable; PLWD and their families are treated as partners in their care in hospital and on discharge; PLWD and their families have an assessment of needs translated into care delivery; care is person-centred and meets individual needs; the environment is comfortable, supportive, promotes well-being and independence; governance structures are in place to support improvement of quality of care, including resources that support staff to deliver care; volunteers with dementia training are available to support activities and pastoral care to compliment, not substitute, paid staff care. | Yes, documenting the NICE guidelines and referencing the VIPS Framework (Brooker and Latham, 2016). | Yes, under the care recommendation it states that drinking should be monitored carefully, and assistance provided as appropriate. |
| Dementia: assessment, management and support for PLWD and their carers. (NICE, 2018) | NICE provides best practice guidelines developed from evidence. They cover diagnosing and managing dementia, with the aim of improving care, providing recommendations for staff training and help for relatives. | The practice guidance is underpinned by the principles of PCC. There are recommendations about distinguishing delirium and dementia for people in hospital with a cognitive impairment. The document explains that there are risks during hospital admission for PLWD, including increased delirium, and suggests that when assessment is made to balance the medical needs with the potential harms the PLWD may face if admitted to hospital. There are links to additional documents for treating delirium included. The document provides guidance on managing transitions between hospital settings and other care settings and provides a link to documents with guidance. | Yes, uses the VIPS Framework. Reports care and support providers should train staff in PCC. | Yes, under the section about palliative care it advises encouragement and support for PLWD to eat and drink. It also suggests involving a speech and language therapist if there are concerns. In the linked advice about treating delirium, the importance of fluid intake is discussed, and a recommendation made to encourage the person to drink to avoid dehydration. |

| Document reference and title | Objective of document | Key points about hospital care for PLWD | Does it advocate PCC? | Are there any points related to fundamental hydration care? |
|---|---|--|--|--|
| <p>National audit of dementia care in general hospitals 2018- 2019: Round four audit report (Royal College of Psychiatrists [RCP], 2019)</p> | <p>This is the report from the RCP's fourth audit looking at the quality of dementia care in general acute hospitals. It focusses on areas of care delivery which are known to affect PLWD when they are admitted to hospital. Recommendations are made based on the results.</p> | <p>There were improvements in the results from the round three audit in 2017. The whole document is relevant so only selected, general aspects are documented here.</p> <p>There were seven themes:</p> <ol style="list-style-type: none"> 1) Relative rating of patient care: 73% of relatives said overall care was excellent or very good. 2) Assessment: physical assessments were documented more than mental assessments. 43% of patients received all possible assessments. 3) Information and communication: 97% of hospitals said they had a formal system to collect personal information to improve care. Case note audit reported 61% of PLWD had this information in place. 4) Staffing and training: 53% of hospitals were able to provide a proportion of staff trained in dementia. 5) Nutrition: the average nutrition score, based on provision of finger food, the presence of protected mealtimes and allowing the relative to visit to provide support, was 89%. 77% of staff reported nutrition and hydration needs of PLWD were communicated 'always' or 'most of the time' at handovers. 6) Discharge: average score based on involving the PLWD, their relative and the MDT in discharge planning and discussion was 76%. 7) Governance: hospital care score of 68%, based on resources and initiatives that demonstrate leadership and support for planning and provision of dementia care. | <p>Yes, discusses the NICE (2018) guidelines use of staff having training about PCC.</p> | <p>Food and drink preferences were recorded in 48% of personal information records for a PLWD.</p> <p>In relative's comments on patient care, 8% stated that the PLWD they care for was not helped with food and drink during admission. 1% said the person they cared for was helped with food and drink. There was also information about food and drink available for relatives; 7% of relative comments said that food, drink or another facility was provided for them. 11% said food, drink or another facility was not provided for them.</p> <p>5% of staff suggestions related to nutrition and hydration, connected to equipment, access, choice and systems to show and record nutritional need. 51% of staff wanted to utilise relatives more often in patient care, including involving them with assistance for eating and drinking.</p> |

This selection of documents demonstrates that across governmental, charity and professional organisations there has been and remains ways to improve dementia care within hospitals but there is still work to be done.

1.8 Summary of thesis

Chapter one has provided background to the two overarching and linked topics explored and investigated through this thesis. Firstly, oral hydration, which is situated as a biopsychosocial need and as a fundamental aspect of care, with specific cruciality for OPLWD. Secondly, dementia, focussing on dementia care within acute hospitals, including an introduction of PCC, as this is considered the optimal approach to dementia care. These topics were then situated within a national policy context.

Chapter two presents the literature concerning hydration care for PLWD in acute hospitals. Due to a lack of primary research about hydration for this population within an acute hospital setting, the chapter presents an integrative literature review exploring hydration care for older people in hospital and long-term care settings. The chapter concludes that there is a dearth of research about this topic within hospitals, and that the available research has not included the concept of PCC, leading to the research aims and questions which end this chapter.

Chapter three further examines PCC by providing an overview of this approach to dementia care through a discussion of the work of Kitwood (1997). A contemporary definition of PCC, the VIPS Framework, is provided (Brooker and Latham, 2016). Alternative frameworks of PCC are considered, and a justification for the use of the VIPS Framework to define PCC within this thesis is made. The provision of PCC for

PLWD in acute hospitals is reviewed through an umbrella review. A further justification for bringing the concepts of hydration and PCC together to explore the care for OPLWD within hospitals is provided.

Chapter four describes and justifies the methodological decisions taken to investigate person-centred hydration care for OPLWD within acute hospitals. The paradigm which the study is positioned within is discussed and the methodological justification for utilising a multiple case study (Yin, 2014). is provided. The multiple data collection methods required to explore the topic in-depth within and across three wards (cases) and the context of the hospital are discussed. The ethical and practical decisions taken are communicated. Reference is made to the concept of rigour and how this was achieved. The chapter concludes with detailing the analytical approach taken to analyse the findings and how the findings were integrated.

Chapter five is the first of two chapters presenting the research findings. This chapter presents the contextual findings which demonstrate the position of hydration care at an organisational level. The ward level findings are then presented to illustrate how hydration care is situated at a ward level. The distinct roles that staff have when carrying out hydration care for OPLWD are presented in a typology, with an argument presented that these siloed roles lead to it being unclear who had responsibility of hydration care within acute hospital wards.

Chapter six provides the findings about hydration care from the OPLWD, individual care level. A framework for how person-centred hydration care within acute hospitals can be achieved is provided. The strategies and barriers to achieving this are described.

Chapter seven revisits the research questions, to answer them systematically. The discussion furthers the understanding of the phenomenon of person-centred hydration care within acute hospitals through answering the questions. The understanding of hydration care for OPLWD in acute hospitals is advanced by situating the research findings and answers to the research questions alongside the previous research which had been introduced in chapters two and three.

Chapter eight concludes the thesis by summarising the original contributions offered to new knowledge generated through this thesis. The strengths and limitations of the study are addressed. Recommendations are made for clinical practice, research, education and policy. The plans for dissemination are described and the thesis ends with a final conclusion.

1.9 Chapter summary

The chapter started by introducing the central concept of the thesis, that hydration is a fundamental care need connected to relationships and interactions when a person is admitted to an acute hospital. Hydration as a concept was introduced, with a view that it is not only physiologically important but also has social importance. I then positioned myself as a researcher, setting out my previous healthcare and research background in dementia and fundamental care. The chapter continued with an overview of dementia, and then focussed on the care of PLWD when they are admitted to acute hospitals. A range of dementia care policies, strategies and reports are then discussed, with reference to PCC and hydration. This chapter concludes with a summary of the whole thesis in section 1.8. In chapter two research

about hydration care in care settings is presented through an integrative literature review.

2 Integrative literature review: What is the evidence for hydration care for older people in care settings?

2.1 Introduction

Chapter one highlighted that older people living with dementia (OPLWD) are admitted to hospital frequently and when there they are likely to require support with fundamental care, including hydration. Furthermore, aspects of hospital care for people living with dementia (PLWD) could be improved. Consequently, fundamental hydration care for OPLWD is a topic worthy of further exploration.

A literature review provides a systematic way to collate what is known about a topic and identify any gaps in knowledge, enabling research questions to be developed. Once developed, the research methodology can be designed to ensure the answers to the research questions address the gap in existing knowledge. This chapter presents the literature review conducted to explore the existing research about hydration care for OPLWD in acute hospitals. In addition to fulfilling the requirements of a PhD, namely to make a significant, original contribution to knowledge, the knowledge generated will contribute to the applied healthcare research evidence base.

A preliminary search for existing articles in February 2016 demonstrated there were few studies exploring hydration care within acute hospitals for OPLWD, therefore the search parameters were widened. Initially, the parameters were widened to include all older adults, not just those living with dementia who were admitted to acute hospitals. This was justified as there are reasons why hydration care is

important and complex for all older people, and these reasons are also relevant for OPLWD, as discussed in section 1.2; additionally older people in care settings may have a cognitive impairment or undiagnosed dementia (Bickel *et al.*, 2018; Sampson *et al.*, 2009). However, even with widened population parameters there were limited studies identified. Based on the specific hydration status of older adults, as discussed in section 1.2, a decision was made not to further expand the population to include all adults admitted to acute hospitals but to expand the environment parameter. Therefore, the final topic of the literature review was to explore research investigating the hydration care for older adults in hospitals and long-term care settings (i.e. nursing homes and care homes). It is likely that articles retrieved from the expanded participant and environment groups are broadly of relevance to OPLWD. An estimated 70% of people living in care homes are living with dementia (Alzheimer's Society, 2016b) and over 50% of older people in hospital are likely to have some level of cognitive impairment due to depression, delirium or dementia (Goldberg *et al.*, 2012).

2.2 Literature review method

Common to all literature reviews is the objective, critical discussion of research on a specific topic, which contrasts and summarises the findings and places the topic within a specific context (Coughlan *et al.*, 2013). A range of methods can be used to undertake a literature review, selected depending on the question being asked in the review and occasionally the methodologies of the research studies being synthesised (Aveyard *et al.*, 2016). In the early 1990s, reviews were often discussed as being either systematic, reporting on quantitative research, or narrative, reporting literature in a qualitative narrative style, although more recently, other review

methods have emerged (Aveyard and Bradbury-Jones, 2019). This literature review, uses an integrative review method, as described by Whitemore and Knaf (2005).

Integrative reviews enable research of different methodologies or theoretical literature to be summarised, which is of benefit to healthcare research (Whitemore and Knaf, 2005). The stages used to report this literature review in a methodologically rigorous manner are taken from Whitemore and Knaf's (2005, p. 549) adaptation of Cooper's (1998) integrative review method. The stages are: problem identification, literature search, data evaluation, data analysis, presentation.

2.3 Problem identification

This stage involved considering and deciding the aim of the review, the variables of interest and the sampling frame. As discussed in the introduction, the literature review focused on the hydration care older people receive in hospitals or long-term care settings. The aim of the literature review was:

- To explore what is known about hydration care and the way it is delivered within hospitals or long-term care settings for older people or older people living with dementia

As the aim concerns evidence from practice, a decision was made to include only empirical studies, not theoretical literature. The next section describes the stages for searching the literature.

2.4 Literature search

A literature search which is well-defined enhances the rigour of the review (Whittemore and Knafl, 2005). A search strategy should be systematic, explicit, thorough and rigorous. The use of established models can guide the question development and search strategy, ensuring key words which provide a comprehensive search are identified (Aveyard *et al.*, 2016). For this search PICO – population of interest, intervention/issue of interest, comparison/context of interest and outcome of interest – was felt to be most appropriate to develop applicable search terms (Polit and Tatano Beck, 2014). Despite PICO being originally used for quantitative searches it has been found to be applicable to qualitative searches too (Aveyard *et al.*, 2016; Fineout-Overholt and Johnston, 2005; Methley *et al.*, 2014).

The search terms were developed and checked with research supervisors and an older people's healthcare specialist to facilitate a thorough search. Due to the awareness that there was limited literature on the topic the terms were initially kept as inclusive as possible, to include as many possible terms that could refer to hydration care. The databases searched were: British Nursing Index (BNI), Cinahl and Medline; the last search was conducted in January 2021. The databases were chosen for their applicability to nursing, allied health professionals, medical and psychological perspectives. The following terms were combined, with no limitations on date, and limitations on English language only. Initially the whole article was searched for the matching words:

P: age* OR aging OR Alzheimer* OR “cognitive deficit*” OR “cognitive dysfunction” OR “cognitive impairment” OR confusion OR delirium OR dement* OR elder* OR geriatric OR “memory deficit*” OR “memory impairment*” OR “memory problem*” OR “neurocognitive disorder” OR “older adult*” OR “older pe*” OR psychogeriatric OR “senior*”

AND

I: fluid* OR hydrat* OR drink* OR water OR tea OR coffee OR juice OR beverage* OR beaker OR cup OR glass OR “fundamental care” OR “basic care” OR “essential care”

AND

C: hospital* OR “acute care” OR “acute setting” OR inpatient* OR “in patient*” OR ward* OR “healthcare environment” OR “health care environment” OR “care home” OR “residential care” OR “healthcare facility*” OR “health care facility*” OR “care setting*” OR “long term care” OR “long-term care” OR “residential home” OR “nursing home”

AND

O: action* OR activit* OR aid* OR approach* OR assistan* OR care OR carer OR caring OR choice* OR command* OR communicat* OR conduct OR contact* OR deliver* OR enabl* OR engag* OR evaluat* OR experience* OR facilitat* OR family OR implement* OR improv* OR job* OR manag* OR measur* OR method* OR nurs* OR opinion* OR plan* OR polic* OR procedure* OR process* OR relative* OR resource* or scheme* OR service* OR skill* OR strateg* OR support OR system* OR task OR view OR work OR “person-centred” OR “person centred” OR “relationship*” OR “patient-centred” OR “patient centred” OR training OR option OR interaction OR assess*

Following the initial search, large numbers of articles did not match the age group or environment, so the population and context search terms were changed to display findings where the matching words were found in the abstract. The following exclusions were also applied to any papers which had these words:

NOT: cerebrospinal, tau, amyloid, cerebral, CSF, biomarker* - if they were in the abstract.

NOT: Dying, palliative, terminally ill, end of life, - if they were in the title.

As well as database searches, a search of the reference list of relevant articles was also conducted; at least two methods of searching are advocated by Whittemore

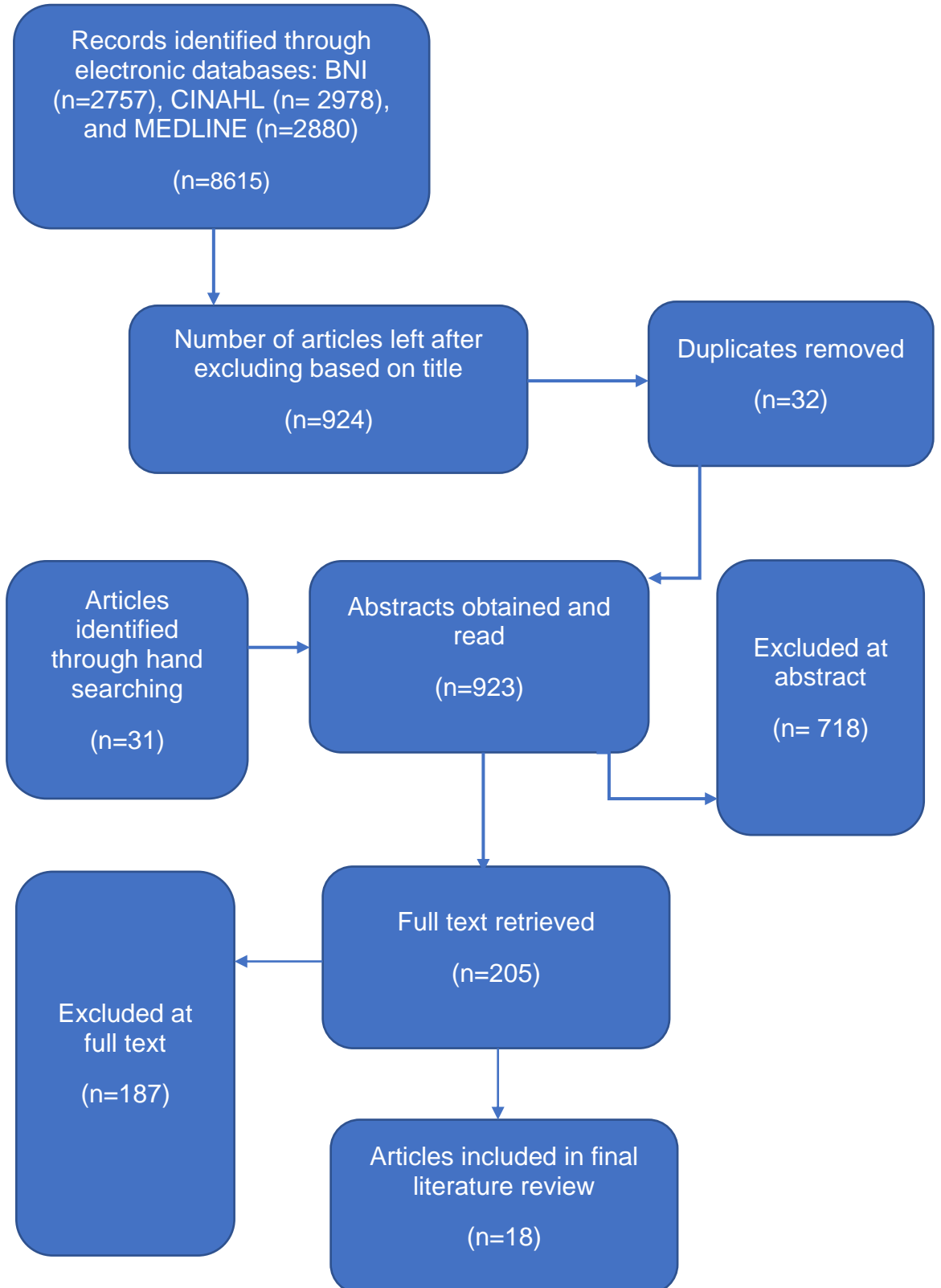
and Knafel (2005). The results of the search are displayed in a PRISMA diagram (see Figure 2.1).

Once the searches were completed the titles were read and any articles which clearly did not relate to the literature review aim were excluded. Completing this involved the development of explicit inclusion and exclusion criteria (Aveyard *et al.*, 2016; Whittmore and Knafel, 2005), displayed in table 2.1.

Table 2.1: Hydration care integrative literature search inclusion and exclusion criteria

| Inclusion | Exclusion |
|---|---|
| Empirical research | Any papers which did not include empirical research |
| The population was 65 years or over, or data relating to this population could be extracted. | Any research reporting only the care needs of people with: <ul style="list-style-type: none"> • dysphagia • receiving end of life care • receiving artificial nutrition or hydration or reporting only on nutritional supplements These topics are of specialist interest and have unique ethical and management considerations. |
| The hydration care of older people in a care setting was observed, reported or views about hydration care from the perspective of the older person, staff or relatives was explored through the research. | Any research reporting intervention only studies |
| The study explored contextual issues relating to the delivery of hydration care for older people in care settings. | Any research investigating clinical screening or assessment of dehydration, without reporting on care delivery. |
| Published in English | Any research related to mealtimes, nutrition, or energy intake without the ability to extract data relating to hydration care. |
| | Any research within community care settings such as within people's homes or day centres. |

Figure 2.1: PRISMA diagram for literature search on hydration care integrative review



2.5 Data evaluation stage

Data evaluation is a common part of literature reviews and many tools have been developed to aid evaluation of published literature. Most tools provide scores, although how to utilise the scores and whether articles are excluded based on the scores are the choice of the reviewer (Whittemore, 2005; Whittemore and Knaf, 2005). For this review, which had mostly descriptive and cross-sectional quantitative research, qualitative or mixed methods research, there was one tool identified that could assist with the assessment of all these types of research: the mixed methods assessment tool (MMAT) (Nha *et al.*, 2018). This was chosen as preferable to using a combination of other tools such as Critical Appraisal Skills Programme (CASP) or Joanna Briggs tools (CASP, 2021; The Joanna Briggs Institute, 2021).

Before using the MMAT, the articles were printed out in full and data were extracted using a data extraction form, developed based on the approach described by Bettany-Saltikov (2012); (see appendix two). This process began with familiarisation with the articles, methodologies, and findings. Once this process was complete, all the articles were re-read and assessed using the criteria from the MMAT, with comments made on the outcomes (Nha *et al.*, 2018). In keeping with the tool recommendations, no articles were excluded if they did not meet the criteria in the tool. Any aspects which affect the quality of the research are discussed in the body of the literature review, as part of the narrative findings. The scores for each article can be found in appendix three.

2.6 Data analysis

The data analysis goal of an integrative review is “a thorough and unbiased interpretation of primary sources, along with an innovative synthesis of the evidence” (Whittemore and Knafl, 2005, p. 550). Thematic analysis was utilised to analyse the literature, through an iterative process to code, group the codes, develop categories and then group the categories into themes which answer the literature review question (Braun and Clarke, 2006). This was completed using computer-assisted analysis software, NVivo 12. The narrative summary presents the findings of the literature review in themes.

2.7 Presentation of results

Table 2.2 displays the articles identified for inclusion in this literature review. The next section will provide a narrative breakdown of the characteristics of the quantitative, mixed-method and qualitative articles.

2.7.1 Quantitative summary

There were nine research articles which reported data from eight quantitative studies in this category - two papers reported findings from the same study. Three articles did not state where the research was carried out. For two, the researchers are based in the United States (US) so it is likely the research was conducted there (Chidester and Spangler, 1997; Spangler and Chidester, 1998). For the third, researchers were based in two countries so the location remains uncertain (Armstrong-Esther *et al.*, 1996). Therefore, there were three studies from the US, two from the UK, one from Australia, one from Canada and one with the country unknown. Most studies were conducted in long-term care settings, with two studies

reporting data from a hospital setting, one being a post-acute hospital. It is unclear if any of the units in the study by Armstrong-Esther *et al.* (1996) were within an acute hospital. Only one study specifically investigated the hydration care of OPLWD (Reed *et al.*, 2005). All studies were cross-sectional, which is partly explained because intervention studies were excluded at the identification stage. Most of the quantitative studies reported the amount of fluid intake of older people in care settings.

2.7.2 Mixed methods summary

Four articles presented studies using mixed methods. Two studies were conducted in the UK (Cook *et al.*, 2019a; Wilson *et al.*, 2020), one in the US, and one in Australia. They all collected data from long-term care homes. Two studies investigated the care for OPLWD (Cook *et al.*, 2019a; Ullrich and McCutcheon, 2008). The aims were to understand hydration care within care homes, apart from Mendes (2006) who described common hydration problems affecting the hydration of nursing home residents.

2.7.3 Qualitative summary

Five articles presented qualitative studies. Three of the studies were conducted in Australia (Bernoth *et al.*, 2014; Lea *et al.*, 2017, 2019); one was conducted in the UK (Godfrey *et al.*, 2012) and one in the US (Mendes *et al.*, 2006). All the articles collected data from long-term care settings, however, the study by Godfrey *et al.* (2012) also presented data from one acute hospital ward. Two of the studies presented data related to the care of OPLWD (Lea *et al.*, 2017, 2019). One study is unique in this category for solely exploring the perspectives of family or friends of older people in long-term care settings (Bernoth *et al.*, 2014). Most studies explored

the views of staff members about hydration care practice, however, two studies explored food and fluid, reporting fluid separately, enabling relevant findings to be included (Lea *et al.*, 2017, 2019).

2.7.4 Summary of results

Most studies were from long-term care settings and the review findings may have been different if more hospitals were included in the identified studies. There were more articles about older people than OPLWD, however, there are likely to be some similarities between these population groups, and there could have been people with undiagnosed dementia within the older participants living in long-term care. Thirdly, the results are from economically developed, English-speaking countries, which may affect the generalisability of the results globally. A narrative summary will be provided of the articles, with the methodologies combined.

Table 2.2: Articles included in the hydration care integrative literature review

| Quantitative | | | |
|---|--|--|---|
| Reference and Country of Study | Research Design and Methods | Study Aims and Objectives | Participants and Setting |
| (Armstrong-Esther <i>et al.</i> , 1996) Country not stated | Cross sectional: measuring fluid intake through direct observation, questionnaire. | To investigate fluid intake in different care settings, and to investigate nurses' knowledge about fluid requirements, needs and monitoring for inadequate intake. | One psychogeriatric unit, one long-term care unit, one geriatric admission unit: 57 elderly patients, 47 nurses. |
| (Beattie <i>et al.</i> , 2014a) Australia | Cross-sectional: Survey. | To identify staff knowledge of nutritional needs of older residents; mealtime practice; attitudes towards mealtime practices and organisation. | One residential care home: 76 staff members. |
| (Chidester and Spangler, 1997) Country not stated (ethics from a university in US) | Cross-sectional: direct observation of food and fluid intake, data extraction of medications, cognitive skills, physical locomotion and ability to understand from medical records. | To compare actual fluid intake of elderly people in a nursing home with three established standards of adequate fluid intake. | Nursing home: 40 residents. |
| (Gaff <i>et al.</i> , 2015) UK | Cross-sectional service evaluation: measurement of fluids provided and consumed, observation or presentation and encouragement of intake. | To evaluate fluid provision and consumption in elderly patients, to determine if current strategies are adequate or modifications are required. | Three orthopaedic rehabilitation wards in one post-acute, long-stay hospital: 58 patients. |

| Reference and Country of Study | Research Design and Methods | Study Aims and Objectives | Participants and Setting |
|--|--|--|--|
| (Gaspar, 1999) US | Cross-sectional: non-participant observation using two investigator-developed data-recording instruments, chart review of measurements (weight, height, urine output), completion of a pressure-score scale. | To explore the adequacy of water intake and identify variables associated with adequate water intake. | One urban nursing home, two rural nursing homes: 99 residents. |
| (Jimoh <i>et al.</i> , 2019) UK | Cross-sectional: MMSE, physical assessment for signs of dehydration, blood sample, observation of drink consumption, asking about the health of participants, usual drinks schedule of the home, observation and weight of drinks consumed. | To document the drinking patterns of older people in long term care and compare patterns for those drinking well to those not drinking enough. | 56 care homes: 182 residents. |
| (Namasivayam-MacDonald <i>et al.</i> , 2018) Canada | Cross-sectional: observation including weighed and estimated food and fluid intake, staff recording of food and fluid out-of-hours, questionnaires, scales and checklists. | To report the average fluid intake of long-term care residents, the proportion consuming less than recommended and the factors associated with fluid intake. | 82 units in 32 long-term care homes: 622 residents. |
| (Reed <i>et al.</i> , 2005) US | Cross-sectional: structured meal observation. | To assess resident, staff and environmental characteristics associated with low food and fluid intake. | 35 residential care and assisted living facilities, 10 nursing homes: 407 residents living with dementia. |

| Reference and Country of Study | Research Design and Methods | Study Aims and Objectives | Participants and Setting |
|--|--|--|---|
| (Spangler and Chidester, 1998) (Country not stated, researchers based in US University) | Cross-sectional: direct observation of food and fluid intake, data extraction of medications, cognitive skills, physical locomotion and ability to understand from medical records. | The paper expands the findings from Chidester and Spangler (1997) to explain eating and drinking behaviours associated with, or that may result in possible dehydration. | One nursing home: 40 residents. |
| Mixed methods | | | |
| (Cook <i>et al.</i> , 2019a) UK | Sequential, exploratory, mixed methods: survey, semi-structured interviews. | To scope and explore hydration practice within care homes. | 18 residential nursing homes, 11 residential dementia nursing homes, 54 staff members. |
| (Mentes, 2006b) US | Descriptive, observational study: recording and measuring urine specific gravity and colour, bioimpedance, meal intake recordings, chart abstraction, field notes and informal staff interviews. | To establish a six-month prevalence of dehydration and to describe common hydration problems of nursing home residents. | Two nursing homes: 35 nursing home residents Nursing staff- number not reported. |
| (Ullrich and McCutcheon, 2008) Australia | Descriptive, observational study: observations using an observational data collection tool, documentary analysis from care plans. | To determine what registered nursing, enrolled nurses and care workers do to promote oral fluid for residents with dementia. | One high-care dementia unit within a residential care home: 7 residents, 10 care workers, one enrolled nurse. |

| Reference and Country of Study | Research Design and Methods | Study Aims and Objectives | Participants and Setting |
|---|--|---|--|
| (Wilson <i>et al.</i> , 2020) UK | Pragmatic, descriptive, observational design: non-participant observation, recording the volume of fluids offered and consumed in a day, semi-structured discussions, testing resident's drinks preferences. | To gain an understanding of practice and the barriers and facilitators influencing the amount of fluid served to and consumed by residents. | Two care homes: Recording of fluids: 16 residents Non-participant observation: 59 residents. Interviews: 27 residents and family members. Cold drink preference testing: 47 residents. |
| Qualitative | | | |
| (Bernoth <i>et al.</i> , 2014) Australia | Phenomenological: unstructured interviews. | To explore the perspectives of family and friends with a loved-one living in a residential care home, or the impact on families when an older person leaves a rural community to access residential care. | 43 participants who had a family or friend living in a residential care home. |
| (Godfrey <i>et al.</i> , 2012) UK | Multi-method qualitative design: interviews, focus-groups, suggestion box and observation. | To understand the issues associated with the hydration and hydration care of older people. | One care of the elderly ward in an acute hospital, one care home 21 older people, 21 nurses and healthcare assistants. |
| (Lea <i>et al.</i> , 2017) Australia | Focused ethnographic, single-case study: interviews, observation, document audit and medical file review. | To evaluate the nutritional status and needs of a person living with dementia in a care home, including barriers and strategies to PCC. | One care home: 1 resident living with dementia, 6 care staff (care, worker, diversional therapy assistant, chef, enrolled nurse, two registered nurses). |
| (Lea <i>et al.</i> , 2019) Australia | Qualitative study: semi-structured interviews, questionnaire. | To explore the awareness of care home staff regarding daily food and fluid care needs of older people living with dementia. | One care home: 11 staff (2 care workers, 2 enrolled nurses, 2 registered nurses, 2 diversional therapy assistants, 3 hospitality staff). |

| Reference and Country of Study | Research Design and Methods | Study Aims and Objectives | Participants and Setting |
|-------------------------------------|--------------------------------------|---|---|
| (Mentes <i>et al.</i> , 2006) US | Descriptive design: focus groups. | To gain the perspectives of nursing home staff about the problem of dehydration and their views on clinical intervention to ensure residents consume adequate fluids. | Three nursing homes: 28 staff (22 certified nursing assistants, 2 licenced vocational nurses, 2 registered nurses, 2 dietary and medical records personnel). |

2.8 Findings

The themes identified from the integrative literature review are documented in table 2.3.

Table 2.3 Integrative literature review findings: hydration care for older people in care settings

| Findings | Subtheme |
|--|--|
| Individuals regularly consume insufficient fluid | The consumption of fluids |
| | Factors influencing fluid intake |
| Organisational and structural aspects of hydration care | Delivery or process of providing drinks |
| | Assessments, care plans and monitoring may be inadequate or inaccurate |
| A variety of roles and knowledge | Discrete roles |
| | Knowledge of risks |
| Hydration is accompanied by personal views | Views and concerns of the older person |
| | A range of preferences |
| | Relatives' roles and views |
| Strategies for hydration care | Approach |
| | Assistance |
| | Communication |
| | Organisational |
| | Environmental |
| | Resources |
| | Relatives |
| Barriers to hydration care | Approach |
| | Assistance |
| | Monitoring |
| | Communication |
| | Individual |
| | Organisational |
| | Environmental |
| | Resources |
| Relatives | |

The findings will now be discussed.

2.8.1 Individuals regularly consume insufficient fluid

2.8.1.1 *The consumption of fluids*

Total consumption of fluids was reported in a large proportion of the studies (Armstrong-Esther *et al.*, 1996; Chidester and Spangler, 1997; Gaff *et al.*, 2015; Gaspar, 1999; Jimoh *et al.*, 2019; Menten, 2006b; Namasivayam-MacDonald *et al.*, 2018; Reed *et al.*, 2005; Wilson *et al.*, 2020). The articles differed because they were conducted in various settings, used different measures of adequate fluid intake, some included fluid from food and drinks, others from drinks only, or had a different categorisation of participants. These varieties make it challenging to compare the articles alongside one another to generate meta-analysis. However, the papers all concluded that older people within care settings regularly do not consume sufficient fluids.

Many studies calculated fluid intake from food and fluid. In Chidester and Spangler's (1997) study, which recorded fluid intake from food and drinks and compared the intake to three standards, they identified evidence of inadequate intake (in 52% of subjects under the first standard, 60% in the second and 90% under standard three). In this study any participants with acute illness, infections or being enterally fed were excluded, although it is unclear how many exclusions resulted in total. The study demonstrates the differences in the standards available to determine sufficient intake. Gaspar (1999) compared water from food and fluid intake to a calculated standard which considers the body surface area; they found only 8% of the participants met or exceeded the required intake. When they calculated water from fluid intake only, they found that more than half of the subjects consumed less than the recommended 1500ml of fluid per day (Gaspar, 1999). Across their sample of

622 residents, Namasivayam-MacDonald *et al.* (2018) found none met the recommended standard for daily water intake. This was in a sample with stringent exclusion criteria such as being medically stable, having lived in the home for over a month, eating an oral diet and typically consuming meals in the communal dining room. Wilson *et al.* (2020) reported that for 14 observed residents in care homes, only one had fluid intake which met the recommended standard.

Other studies recorded fluid intake from drinks only. When fluid intake from drinks consumed by older people across three settings were recorded, Armstrong-Esther *et al.* (1996) found the mean fluid intake was below the recommendation in all three settings. In a study of older people in long-term care, Jimoh *et al.* (2019) found 55% of participants had fluid intake that met the recommended total. In a study of OPLWD, food and fluid intake were observed and any participant who consumed ≤ 8 oz. of fluid was recorded as having low fluid intake. In the sample of 407 OPLWD, 51.3% had low fluid intake. When the sample was split between residential care and nursing homes, a significantly lower proportion of participants in the residential care homes had low intake compared to the nursing home. Mentis (2006) recorded the fluid intake consumed during six mealtimes and categorised the participants into four groups with seven sub-groups to develop a typology of drinking problems. They found, participants in all four groups drank an average of 50-60% of the fluids offered during mealtimes.

Gaff *et al.* (2015) was the only study that recorded intake from a hospital, a post-acute rehabilitation setting. They found the mean intake of 58 patients was significantly lower than the recommended standard with 35 out of the 58 patients consuming < 1500 ml per day and 14 consuming < 1000 ml.

Although there are numerous standards to consider adequate fluid intake, the evidence demonstrates that whether calculated from food and fluid or fluid only, older adults in care settings frequently consume less than the recommended amount of fluid. In addition to the quantity of fluids, many articles examined factors that potentially affected fluid intake, discussed in the next section.

2.8.1.2 Factors influencing fluid intake

The research findings presented in the previous section described the amount of fluid that participants consume from several studies. These studies also collected demographic information or other measurements about a person to determine if there were any characteristics or other factors which may contribute to variations in older people's fluid intake. The settings, countries, participants, and measurements collected all varied; additionally, some papers have conflicting findings therefore, it was not possible to develop generalisable conclusions. However, the findings are presented for consideration.

There was variability in whether individual characteristics influenced fluid intake. Reed *et al.* (2005) found no characteristics were associated with low fluid intake, whereas Namasivayam-MacDonald *et al.* (2018) identified several characteristics associated with low fluid intake. Namasivayam-MacDonald *et al.* (2018) hypothesised that urinary incontinent participants would have lower intake, but this was not an association found in their data. In contrast, Armstrong-Esther *et al.* (1996) found participants with incontinence had lower intake on two of the three units they collected data from, although they found that being older was not significantly associated with fluid intake. Chidester and Spangler (1997) also found no association between fluid intake and age. However, Namasivayam-MacDonald

et al. (2018) found that with every year increase in age, fluid intake declined by 6ml per day.

Namasivayam-MacDonald *et al.* (2018) found a significance in the difference between male and female intake, with males consuming approximately 119ml more a day. Gaff *et al.* (2015) also noted males had a higher intake than females, but found no significance ($p= 0.052$). Jimoh *et al.* (2019) reported that males had a higher mean intake than females, but this was not significant ($p=0.66$). Another study found that on two of the three units data were collected, females had higher intake than males, although this was not a significant difference (Armstrong-Esther *et al.*, 1996).

Cognition was another factor measured. Armstrong-Esther *et al.* (1996) found that on two of the three care 'units', participants who were confused consumed significantly less than non-confused participants. A moderate to severe cognitive impairment was also found to reduce intake of up to 70 millilitres ($p<0.05$) (Namasivayam-MacDonald *et al.*, 2018). Godfrey *et al.* (2012) observed that fluid intake was hindered by participants being fatigued or sleepy.

Several studies examined the support that participants required with fluid intake. Armstrong-Esther *et al.* (1996) reported a significant correlation between being dependant and having a low fluid intake. However, Wilson *et al.* (2020) found that the mean volume of fluids served was 1512ml, and those who required assistance consumed 80.5% of the fluids served, independent participants consumed 68%, and those who required prompting consumed 54%, however the sample was small ($n=14$). Namasivayam-MacDonald *et al.* (2018) found that participants who "often" needed assistance during meals drank significantly more than those who

“never/rarely” or “sometimes” required assistance. As well as their findings about participants “often” needing assistance, drinking more, they used a questionnaire called Ed-FED which found participants who had a higher number of problems associated with eating had a decreased fluid intake; for each one-point increase in score they found a significant decrease of 62ml of fluid intake.

Mentes (2006) created a typology to categorise participants into groups and sub-groups which describe their hydration intake and needs. They found most groups consumed between 50 - 60% of the fluids offered during mealtimes, although one subgroup, the “Sippers” drank only 25% of fluids, all of whom reported never having consumed many fluids. An additional variable measured by Chidester and Spangler (1997) was that there was a significant correlation between the number and frequency of medications and non-meal fluid intake.

Based on the research, there is no strong evidence to conclusively ascribe any individual characteristics with an increased risk of reduced fluid intake, although, a cognitive impairment was found to increase the risk significantly. The findings support that an individual approach to hydration care is required.

Some studies reported differences in fluid intake based on the location, setting, and staffing but these were not comparable.

Reed *et al.* (2005) found residents having meals in dining rooms were significantly less likely to have low fluid intake when compared to residents having meals in their own rooms. They also found residents drinking in dining areas with more non-institutional features were less likely to have low fluid intake. One surprising finding by Namasivayam-MacDonald *et al.* (2018) was that having more staff in the dining

room was associated with a significant decrease in fluid intake, however, the authors recognised a higher number of staff was likely to reflect increased residents with disabilities or larger dining rooms, which may explain this phenomenon. Perhaps for similar reasons, Reed *et al.* (2005) found a significantly lower proportion of those in residential care and assisted living had low intake compared to those in nursing homes. Within the residential homes, more residents had meals in dining areas, there were fewer non-institutional features, there were more people in a low-noise environment, and fewer participants received pureed food in comparison to nursing homes. Wilson *et al.* (2020) found that residents in their own rooms who required assistance to drink had the lowest mean intake (660ml), although their sample was small. Another comparator found residents in homes that were for-profit were less likely to have low fluid intake (Reed *et al.*, 2005). Finally, within hospital, consumption of hot and cold fluids from the trolley was significantly higher ($p < 0.0001$) than those consumed from the jugs, with 77% of the drink consumed when served from the trolley compared to 41% of the water from jugs (Gaff *et al.*, 2015). However, the amount of fluid available in the jug was larger than the volume of drinks offered by the trolley.

This section focussed on consumption of fluids, reporting individual or other contextual factors which may influence intake. The data indicates staffing, environment and type of drinks may influence intake. Due to the different comparators used in the various studies, no findings from pooling data can be calculated. As well as fluid intake, there are other areas to consider for hydration care.

2.8.2 Organisational and structural aspects of hydration care

2.8.2.1 Delivery or process of providing drinks

The way drinks were provided within the care settings was mostly described as following a predictable routine (Armstrong-Esther *et al.*, 1996; Godfrey *et al.*, 2012; Jimoh *et al.*, 2019; Wilson *et al.*, 2020). One participant in Godfrey *et al.* (2012, p. 1204) used the word “regimented” to describe the drink process; the authors found in both the care home and the hospital ward that there was a reliance on the drinks trolley to provide oral hydration. The view of staff, particularly healthcare assistants, was that hydration care was one of many “tasks” or “chores” and other tasks such as assisting with food or changing a person’s pad were completed alongside hydration care and these additional tasks were potentially viewed as having higher priority (Godfrey *et al.*, 2012, p. 1206). Within hospital settings, in addition to hot and cold drinks being offered five-to-six times throughout the day from a trolley, covered jugs of cold water were also provided (Gaff *et al.*, 2015; Godfrey *et al.*, 2012).

Mealtimes were found to be an important time for fluid provision (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Jimoh *et al.*, 2019; Wilson *et al.*, 2020). Some studies noted the fluid content of food was also important. Armstrong-Esther *et al.* (1996) found 79% of total daily fluid offered came from meals and Wilson *et al.* (2020) found 33% of fluids consumed came from foods. Staff recognised some food supplies fluid (Godfrey *et al.*, 2012). Cook *et al.*, (2019a), reported staff discussed the importance of meals for fluid intake and said the food menu reflected this by having foods incorporating a high fluid content. Other studies found drink offers peaked at mealtimes (Jimoh *et al.*, 2019; Wilson *et al.*, 2020). Jimoh *et al.* (2019) identified that, although 75% of drinks were offered with meals, most drinks were consumed

at non-mealtimes. This reflected Godfrey *et al.* (2012, p. 1204), who described drinks at mealtimes being “erratically drunk.” Additionally, Wilson *et al.* (2020) explained hot drinks were rarely offered with meals other than breakfast, which may conflict with resident preferences, discussed in section 2.8.5.2.

Fewer drinks were offered at night, accounting for 4% of drinks in the Jimoh *et al.* (2019) study. Armstrong-Esther *et al.* (1996) found no participants received fluids before 6am or after 6pm, other than <30ml with medications. The small volume of fluids associated with medications was also noted by Godfrey *et al.* (2012), however, Jimoh *et al.* (2019) found drinks consumed with medications formed 10% of total fluid intake. One participant felt the last drink offered in the hospital at 9pm was too early (Godfrey *et al.*, 2012); the authors also noted that in hospitals snacks were not offered as part of drinks rounds which contrasted with the care home.

Jimoh *et al.* (2019) found the drinks offered to residents would not be sufficient to meet their daily requirement, meaning residents would have to help themselves to drinks to meet adequate intake. However, in a questionnaire completed by 47 nursing staff, although 76% believed elderly patients should receive a drink when asking for one, rather than solely during routine rounds, only 57% said they provide a drink to patients when asked (Armstrong-Esther *et al.*, 1996). A relative in another study reported a problem with drinks rounds, explaining that the staff in their family member’s care home had decided they were too busy to complete a morning and afternoon drinks round and stopped providing this; the managers were unaware until relatives alerted them (Bernoth *et al.*, 2014). Another issue reported with drink rounds was that drinks offered between meals were only to independent drinkers; those sleeping were not awoken for a drink and bed-bound participants were not

always positioned to reach or consume their drink (Wilson *et al.*, 2020). In an in-depth, ethnographic single case study of an OPLWD, Lea *et al.* (2019) observed staff offering the OPLWD a drink that was not their preference and then, when they were given their preferred drink, it was left out of reach. Similar issues, such as bottles of water being provided but left out of reach or remaining unopened due to residents' dexterity issues were reported by relatives (Bernoth *et al.*, 2014).

There was little evidence to describe the approach staff took when offering drinks, although Godfrey *et al.* (2012), through observing care, explained that moments for social interactions were missed in the facilitation. Ullrich and McCutcheon (2008) also observed care and found 89.7% of care worker interactions were friendly and open on approach, although this declined to 74% remaining friendly and open as the process of assisting with oral fluids progressed. Wilson *et al.* (2020) found there was little opportunity for residents to express autonomy in drinks choices, particularly as limited choices were offered, even though choices were available. Jimoh *et al.* (2019) reported two sets of data and found the mean number of drink varieties consumed was 3.5 or 4 drink types per day, with tea, water and coffee accounting for 70% of the total beverage intake.

Cook *et al.* (2019a) had unique findings from the two care homes they recruited, as they reported a range of beverages on offer such as hot chocolate, milkshakes, lemonade, orange juice, lemon juice, blackcurrant, mango and pineapple. The staff also reported the importance of a variety of flavours, textures, temperatures, and colours. In contrast to the routine and regimented approaches reported elsewhere, staff explained that they consciously increased intake when residents were ill, there was hot weather, residents were on trips and that fluids were offered as part of

activities and full cups were offered with medications (Cook *et al.*, 2019a). Godfrey *et al.* (2012) reported ways hydration care could contribute to dignity through the approach to offering drinks, by recognising preferences, ensuring people are in comfortable positions and allowing adequate time to finish drinks.

Related issues, such as the receptacle drinks were provided in, could influence the experience of drinking. Issues could include difficulty holding cups and saucers (Godfrey *et al.*, 2012; Wilson *et al.*, 2020), having a lack of choice in the type of receptacle, which were predominantly uniform and bland (Godfrey *et al.*, 2012), or having drinks served in dirty or stained cups (Bernoth *et al.*, 2014). Additionally, drinking aids such as beakers with spouts may harm a person's self-identity, as one participant described entering their "second childhood" when discussing drinking with a beaker (Godfrey *et al.*, 2012, p. 1207). The aids provided may also underestimate a person's abilities, Lea *et al.* (2019) found an OPLWD was provided a cup with two handles, however they only required the use of one handle.

These findings demonstrate that the process and delivery of fluids was mainly described as routinised and this could disadvantage some. There were potential risks to dignity through the way drinks were provided, although there were opportunities to adapt the routines to facilitate individualised care and support dignity. A further aspect of hydration care, the use of assessments, care plans, and monitoring, will now be presented.

2.8.2.2 Assessments, care plans and monitoring may be inadequate or inaccurate

Assessments, care plans and monitoring were identified as a way of contributing to nutritional or hydration care across the settings, although the formal processes were not clearly reported.

2.8.2.2.1 Assessments

Assessments were reported in the studies examining nutrition or food and fluid, which had reporting about hydration included (Beattie *et al.*, 2014b; Lea *et al.*, 2017; 2019). As such, the reported assessments were weighted to nutrition and nutritional risk assessments. Of the 76 staff surveyed by Beattie *et al.* (2014c), 83% reported nutritional assessments were important, although only 52.9% reported carrying these out; the most common assessment related to weight loss. The assessment related to hydration was fluid intake/output but only 38% said they carried this out (Beattie *et al.*, 2014a). Fluid intake/output recording is further discussed in 2.8.2.2.3. Reed *et al.* (2005) discovered residents in residential or assisted living homes were significantly less likely to have formal assessments for drinking difficulties compared with nursing homes.

Staff may have additional methods to monitor dehydration, such as looking for dry lips or skin, the tongue, a catheter, skin or for sunken eyes (Godfrey *et al.*, 2012). Wilson *et al.*, (2020) found that neither of the two care homes investigated had a system for identifying or responding to low fluid intake. This is of concern, as Jimoh *et al.* (2019) found there was no correlation between staff-reported risk of dehydration or requiring help with drinking and actual dehydration, which suggests it may be challenging for staff to predict those at risk of dehydration.

In addition to clinically based assessments, staff in the Lea *et al.* (2017) study described the importance of getting to know a person's food and drink preferences, documenting this and ensuring any change to preferences over time were monitored, which is a person-centred approach. Findings related to any formulated or actioned hydration care plans will now be presented.

2.8.2.2.2 Care plans

Only one study reported on the content of hydration care plans, comparing nursing care for seven residents living in a 20-bed residential dementia care unit with the care documented in their care plan (Ullrich and McCutcheon, 2008). Whilst there were examples of other care plans being actioned, such as providing straws or beakers for residents requiring assistance (Lea *et al.*, 2019; Wilson *et al.*, 2020), or staff providing additional fluids when residents were unwell or physically inactive (Cook *et al.*, 2019a), it was unclear how these were documented, communicated or actioned.

Ullrich and McCutcheon (2008) found nurses were the staff who wrote the care plans but were not the staff group implementing the most direct care. They found some differences in documentation and actions. One aspect they reported was the position of the care workers when providing fluid to residents, which they found varied between sitting or standing and at 45° or 90° angles. They reported that there was no guidance in the care plans about which position was recommended for care workers to be in when providing hydration care. They observed non-verbal interactions being implemented but found only one of the care plans specified "eye contact" or "lots of smiles" as an aspect of care required for hydration (Ullrich and McCutcheon, 2008, p. 2913). The authors combined the observed verbal

interactions used to facilitate hydration into one descriptor, “helping the residents to connect with the reality of fluid intake” (Ullrich and McCutcheon, 2008, p. 2913) and found the written care plans reflected this type of care that was being carried out. They also found all residents required continuous assistance, which most care plans had documented as “1:1 assistance throughout all eating and drinking” (Ullrich and McCutcheon, 2008, p. 2914). One intervention, which was observed for five participants but was only documented in two care plans, was the “hand-over-hand” technique, although the care plans used more specific ways to describe this action (Ullrich and McCutcheon, 2008, p. 2914). The authors labelled other touch interventions: expressive, necessary, non-necessary and non-procedural touch, giving examples such as gently holding hands, applying a clothing protector, or wiping away spillages. The authors found touch interventions were carried out regularly but not reflected in written care plans (Ullrich and McCutcheon, 2008). Although only one study reported on written care plans, more studies reported the process monitoring fluid intake using charts and the views about this documentation.

2.8.2.2.3 Monitoring

Many studies reported issues related to the use of fluid charts for monitoring fluid intake. Of the 47 nursing staff surveyed by Armstrong-Esther *et al.* (1996), none found fluid balance charts useful as they felt they were inaccurate except for acutely unwell patients. Godfrey *et al.* (2012) and Wilson *et al.* (2020) questioned the accuracy of fluid balance charts. Godfrey *et al.* (2012) observed hospital nurses asking patients or relatives about a person’s intake or filling fluid charts in without it being clear to the researchers how they knew what to record. They found that in both the care home and the hospital, cups were collected by nurses, healthcare assistants or domestic staff without asking the person if they had finished or

documenting the amount consumed. An additional challenge identified by Armstrong-Esther *et al.* (1996) was that only 49% of the 47 nurses surveyed knew the correct fluid capacity of the receptacles being used to provide drinks. One care home had implemented a different coloured jug for morning and afternoon vessels to assist staff with fluid monitoring (Cook *et al.*, 2019a).

The participants who had fluid balance charts in use were only reported in one study (Wilson *et al.*, 2020) which found four of the 14 participants had fluid balance records, although they reflected the drinks offered rather than consumed and the charts were not formally reviewed every day. Despite concerns about the accuracy of fluid balance charts, some staff reported they were in use to monitor intake (Godfrey *et al.*, 2012), and did stress their importance (Cook *et al.*, 2019a).

Cook *et al.* (2019a) identified inconsistencies across care homes about what the daily target fluid intake for residents should be. They found 23 (which was 79%) of care home respondents had a daily fluid target for all residents, of these, 11 (13.6%) were variable, based on individualised need or medical recommendation. However, 9 (11%) used a uniform target daily fluid intake for all residents, which had a range between 500ml and 2 litres per day (Cook *et al.*, 2019a).

These findings demonstrate that the ability to monitor fluid intake may be inadequate or untrusted by staff. Alongside assessments, creating care plans and monitoring fluid intake, staff in a variety of roles will require the knowledge and skills to carry out these tasks which is explored through the next theme.

2.8.3 A variety of roles and knowledge

2.8.3.1 Discrete roles

In a survey of 29 residential and care homes, staff surveyed all reported actively promoting hydration care for residents (Cook *et al.*, 2019a). Although data suggests there are discrete roles staff undertake regarding hydration care, there is a paucity of evidence about what the distinct roles are. Within the hospital setting, Godfrey *et al.* (2012) found giving out drinks was not always delivered by staff in the same job role, which was actioned by either healthcare assistants, domestic assistants or volunteer “coffee-ladies”, causing inconsistencies in approach. Other staff recognised that part of their role was to continually provide fluids, as the routinised rounds did not always provide adequate fluids (Cook *et al.*, 2019a).

Staff in different care homes described how the professionally siloed nature of the discrete roles meant some staff did not recognise when there were issues in areas outside their domain, therefore did not know when changes were required (Lea *et al.*, 2017). This could lead to staff who recognised changes would be beneficial not being able to action them, or having difficulty communicating these to senior staff who could make changes; staff then gave up trying to influence changes within their care home (Lea *et al.*, 2017).

A variety of staff roles are involved in facilitating hydration but there is little evidence to expand on the distinct roles.

2.8.3.2 Knowledge of risks

Staff knowledge and skills were uncovered in studies directly through questionnaires (Armstrong-Esther *et al.*, 1996; Beattie *et al.*, 2014a; Lea *et al.*, 2017; Mentis *et al.*,

2006) or indirectly through staff interviews (Cook *et al.*, 2019a; Godfrey *et al.*, 2012). Staff felt it was important for older people to drink fluids for their health (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Lea *et al.*, 2017) or that dehydration was an important health issue (Mentes *et al.*, 2006). Mentes *et al.* (2006) asked 28 staff to rate dehydration as a health issue for nursing home residents, all staff rated it between eight and 10, with 10 being the most important. When considering health aspects of hydration, staff often identified aspects related to risks, such as choking, with some staff members reporting dysphagia as one of their main concerns (Lea *et al.*, 2017). When staff reported risks associated with low fluid intake or dehydration, they commonly identified urinary tract infections and renal failure (Armstrong-Esther *et al.*, 1996). Staff reported looking for signs of dehydration as part of their daily care interactions (Mentes *et al.*, 2006). Staff education and training topics were focussed on managing risks, Lea *et al.* (2017) asked staff about their nutrition or hydration training or education and found seven of the 11 participants had received training on swallowing and nutrition, including preparing texture modified meals for people with dysphagia. There were no reports of training relating specifically for other aspects of hydration care. When Beattie *et al.* (2014a) surveyed 76 staff on their nutritional knowledge, they found 63% of respondents accurately knew the effects of ageing on hydration status, although the highest score (76%) related to staff knowledge about the risks associated with malnutrition.

Staff in one study felt that older people's hydration levels required an increase and staff education was a way to improve intake (Lea *et al.*, 2017). In another study staff reported some of the specific issues for older people which made sufficient fluid intake important, such as difficulty maintaining thermal homeostasis in a warm room or being prescribed diuretic medications (Cook *et al.*, 2019a).

Staff had some knowledge about the associated risks of low fluid intake, however, the evidence suggests there is little formal training about other topics associated with hydration care.

2.8.4 Hydration is accompanied by personal views

2.8.4.1 Views and concerns of the older person

There were few studies which asked older people their views about hydration directly (Godfrey *et al.*, 2012; Lea *et al.*, 2019; Wilson *et al.*, 2020); other articles reported the staff's opinion of residents' views.

Godfrey *et al.* (2012) evidenced that older people knew the relationship between drinking and health; some participants monitored their own intake, had knowledge about the potential negative impact of low intake or encouraged other residents to drink. However, in another study staff explained residents did not report being thirsty and therefore could miss obtaining fluids (Cook *et al.*, 2019a). This was corroborated by participants reporting they lacked a thirst sensation (Godfrey *et al.*, 2012). Additionally, Jimoh *et al.* (2019) found that when they asked residents "are you currently feeling thirsty?" expression of thirst was not a good indicator for hydration status.

Drinking was rarely reported by older people as pleasurable; it was often perceived as a task or burden (Godfrey *et al.*, 2012). Concerns about being able to go to the toilet worried some participants, 50% (n=10), stated they restricted their intake to avoid going to the toilet or due to incontinence fears (Wilson *et al.*, 2020). Other factors affecting pleasure were taste, temperature, appearance of drinks and the use of drinking aids; participants had individual preferences in these areas (Godfrey

et al., 2012). Individual drinking ability was influenced by the older person's frailty, resulting in a reliance on staff or relatives to pour drinks or assist with other drinking-related tasks (Godfrey *et al.*, 2012). Even in care homes where residents had the opportunity to help themselves or ask for a drink freely, observations indicated residents rarely did either (Jimoh *et al.*, 2019). The experience of being given a drink when not everyone has one was commented upon by Lea *et al.* (2019), who noted the OPLWD they were observing appeared uncomfortable to drink without the researchers also having a drink; the OPLWD offered them some of their own drink twice.

It was not a certainty that drinking had to be a chore or an unpleasant experience. Enjoyment in drinking was noted during a "keep fit and sherry" activity (Godfrey *et al.*, 2012, p. 1202); additionally, the authors found that some drinks evoked pleasant memories for participants. Some participants expressed joy having drinks they enjoyed, having a hot drink in the morning (Wilson *et al.*, 2020) or sharing drinks given as gifts by their family (Cook *et al.*, 2019a).

The evidence demonstrates there are personal feelings, abilities and concerns about hydration which may impact an older person's hydration experience. Preferences related to hydration are discussed next.

2.8.4.2 A range of preferences

There were a range of preferences described within the literature, including the vessel the drinks were provided in, the type and choice of drink, and the timings of drinks. Having a choice of cup, beakers or straws was considered useful; reasons for choosing specific cups and aids varied and some residents would only drink from specific cups (Cook *et al.*, 2019a). Some participants found bigger handles and cups

better, others found plastic difficult to hold while some found it easier, some preferred a cup that did not make any disabilities obvious, and others chose a cup considering the weight or likelihood of spills (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Wilson *et al.*, 2020).

Limitations with the cups available were identified by the researchers. Wilson *et al.* (2020) observed some of the cups provided in the care home were difficult for the participants to hold and Godfrey *et al.* (2012) spoke to a participant who avoided getting drinks from the 'water cooler machine' as the plastic cups associated with it were too difficult to use.

Older people had preferences about the type of fluids they consumed. When asked, 24 of 27 residents said tea was their favourite drink, however, when 47 residents took part in a cold drink taste test the most popular drinks were sweet-tasting juices and flavoured milk (Wilson *et al.*, 2020). Jimoh *et al.* (2019) found that among 174 participants, tea and coffee were the most preferred drinks, while >10% said fruit juice, water, squash or an alcoholic drink were their favourite drinks. Some participants indicated they did not like water, or staff said they did not think older people enjoyed drinking water and could be improved by adding cordial, however the available cordial in the hospital was reported to have a poor taste (Godfrey *et al.*, 2012). One participant explained their drink choice is based on which drink will not discolour their clothing if spilled (Godfrey *et al.*, 2012). Others had preferences for drinks early in the morning or in the evening but were not receiving these due to the drink routine (Godfrey *et al.*, 2012; Wilson *et al.*, 2020).

The temperature of drinks also contributed to enjoyment; cold water was preferable to room temperature, and there was variation between people who preferred hot

drinks cooled with extra milk, or remaining hot, which was a problem if drinks were left while participants were elsewhere when drinks were served (Godfrey *et al.*, 2012). Cook *et al.* (2019a) found ice pops and ice cream were popular with care home residents.

Staff interviewed by Lea *et al.* (2017) understood the importance of gaining and documenting a person's food and drink preference and monitoring any changes over time. However, Wilson *et al.* (2020) found some residents were not receiving their preferences; one participant had, on one occasion, declined tea and was no longer being served it, despite desiring it, another explained they felt they had to drink squash but they did not enjoy it and another was told tea was better for them than their preferred coffee. In another study, Lea *et al.* (2019) witnessed staff not taking into consideration the preferred drink of an OPLWD, who declined the drink offered (which was not her preferred drink) and was later not offered her preferred drink with her medications. Considering a person's preferences required hospitality staff to be flexible (Lea *et al.*, 2017) and observant (Cook *et al.*, 2019a). A nursing home staff member in a focus group said it can be difficult to know day-by-day a person's preference, so a way to overcome this is by offering different options (Mentes *et al.*, 2006).

There are a range of preferences that older people in care settings have when they are receiving a drink. This evidence demonstrates these require consideration in care settings.

2.8.4.3 Relatives' roles and views

Although relatives clearly do have a role supporting hydration, the details of the role that relatives take was underdeveloped within the literature. Only one article

presented the views - of a self-selecting sample - of family or friends of a person living in a long-term care setting; the findings demonstrated the strength of feeling relatives can have when considering nutrition and hydration issues (Bernoth *et al.*, 2014). Relatives spent time within the care settings, sometimes aiding their relatives (Godfrey *et al.*, 2012) which led to them forming opinions about the delivery of hydration care (Bernoth *et al.*, 2014). Relatives could bring in drinks, and support their relative to drink; within a hospital they were also found to keep track of the quantity of fluids consumed to share with staff (Godfrey *et al.*, 2012). Relatives may become concerned about their family member if they are not available to provide this support. One relative explained that they had been requested by another relative who was going away for a week to assist with taking the lid off their mother's water bottle, as they did not feel they could rely on the care home staff to do it (Bernoth *et al.*, 2014). Other relatives described a requirement to be present to assist at mealtimes (Bernoth *et al.*, 2014), however, it is unclear if this was for food only or included support with drinks. Whilst present, the relative may notice aspects of care which are uncomfortable, one relative explained they were aware drinks were left out of reach, drinks offered were not in keeping with preferences and staff did not always prompt the person to drink (Lea *et al.*, 2019). One relative reported they noticed their family member had lost weight, so they requested a doctor to review them, but it did not happen; subsequently they took their relative into a hospital and he was found to be dehydrated among other physical health issues and died shortly after (Bernoth *et al.*, 2014).

In hospital, Godfrey *et al.* (2012) found relatives' roles may be underestimated by hospital staff, who felt volunteers were more important than relatives in helping patients to drink. However, in one care home setting, the care staff reported that

part of their role was promoting the importance of hydration with family and friends of residents, or facilitating the social aspect of providing drinks with relatives, perhaps demonstrating a higher valuing of relatives' roles in promoting hydration care (Cook *et al.*, 2019a).

Across long-term care and hospital settings relatives can provide support with and insight into the hydration care being provided, although more research would be beneficial to further explore this.

2.8.5 Strategies for hydration care

Table 2.4 displays the strategies for hydration care which were presented in the literature. There were a range of strategies which have been grouped into the following categories: approach, assist, communication, environmental, organisational, resources and relatives. The categories will be discussed separately however, some content of the categories link, overlap or rely on an aspect within another category to be facilitated. The first category discussed is approach.

Table 2.4 Strategies for hydration care from integrative literature review

| Reference | Approach | Assist | Communication | Organisational | Environmental | Relatives | Resources |
|--|----------|--------|---------------|----------------|---------------|-----------|-----------|
| (Armstrong-Esther <i>et al.</i> , 1996) | | | | | | | |
| (Beattie <i>et al.</i> , 2014a) | | | | | | ✓ | |
| (Chidester and Spangler, 1997) | | | | | | | |
| (Gaff <i>et al.</i> , 2015) | | | | | | | |
| (Jimoh <i>et al.</i> , 2019) | | | | | | | |
| (Namasivayam-MacDonald <i>et al.</i> , 2018) | | | | | | | |
| (Reed <i>et al.</i> , 2005) | | | | | | | |
| (Spangler and Chidester, 1998) | | | | | | | |
| (Cook <i>et al.</i> , 2019a) | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| (Mentes, 2006) | | | | | | | |
| (Ullrich and McCutcheon, 2008) | ✓ | ✓ | ✓ | | | | ✓ |
| (Wilson <i>et al.</i> , 2020) | | | | | | | |
| (Bernoth <i>et al.</i> , 2014) | | | | | | | |
| (Godfrey <i>et al.</i> , 2012) | ✓ | ✓ | ✓ | | | | ✓ |
| (Lea <i>et al.</i> , 2017) | ✓ | | | ✓ | ✓ | | ✓ |
| (Lea <i>et al.</i> , 2019) | | | | | | | |
| (Mentes <i>et al.</i> , 2006b) | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

2.8.5.1 Approach

These strategies can be determined by the staff member's approach to hydration care. This includes staff consciously being aware of the importance of fluid intake and making an effort to know a person's preferences (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Menten *et al.*, 2006). One approach was making opportunities to promote hydration by fitting hydration into other activities and entertainment such as dominos or summer fayres (Cook *et al.*, 2019a; Lea *et al.*, 2017). In the study by Menten *et al.* (2006b), staff said they provided rewards or incentives to the person to encourage them to drink. There were also times staff took opportunities to increase hydration by providing a full cup of water with medications or being aware when people were ill, or the weather was hot and they might require more fluid (Cook *et al.*, 2019a). Staff may be required to take a flexible approach to individual needs, such as returning to the person several times if they decline care or by providing continuous assistance (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Menten *et al.*, 2006; Ullrich and McCutcheon, 2008). Staff may also provide direct assistance to someone to facilitate hydration care.

2.8.5.2 Assistance

This section is about the forms of physical assistance that staff provide to OPLWD ranging from one off, to more prolonged interventions. This included providing continuous assistance; helping people into a comfortable position to drink; placing a drink into a person's hand; providing hand-over-hand assistance; putting the cup to a person's lips and placing a napkin onto the person to protect their clothing (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Menten *et al.*, 2006; Ullrich and McCutcheon,

2008). Alongside assistance, staff may have used communication as a strategy, this is discussed next.

2.8.5.3 Communication

Communication strategies included verbal communication between staff and older people, between different staff members and between staff and older people's relatives. The strategies between staff and older people involved greeting the person on approach, encouragement throughout the day, asking and offering drinks in an appropriate way, identifying drinks, redirecting and reminding older people to drink (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Mentes *et al.*, 2006; Ullrich and McCutcheon, 2008).

Staff members were noted to be enthusiastic when sharing strategies and tips about promoting hydration for individuals as part of the focus groups; they said they share information usually through word of mouth or in more formal reports to the nurse in charge (Mentes *et al.*, 2006). One nursing home had implemented a coloured glass system to indicate to staff when morning drinks had been changed to afternoon drinks, based on the colour change (Cook *et al.*, 2019a). In one study staff explained that they communicate to relatives the importance of hydration, to promote this aspect of care (Cook *et al.*, 2019a). Beyond individual communication interventions there were also organisational strategies.

2.8.5.4 Organisational

Organisational approaches were strategies outside of the control of the staff members. One organisational approach to hydration care was to include hydration care strategies as part of an older person's review (Cook *et al.*, 2019a). There was a view that as hydration care took time, staff required the time to carry out this aspect

of care; to facilitate this, staff in a focus group suggested that having one person available all day whose role it is to provide drinks would be a solution (Mentes *et al.*, 2006). In one care home there was a breakfast club aimed at supporting OPLWD; as part of this staff could eat alongside the person, and they found this a better strategy than providing assistance only (Lea *et al.*, 2017). Some of the organisational elements are also linked to the environmental strategies.

2.8.5.5 Environmental

Staff described how they perceived alterations to the environment could improve hydration. One strategy was improving the dining room environment by making it more relaxing or playing music (Cook *et al.*, 2019a; Lea *et al.*, 2017). Other alterations were to attempt to increase socialisation and interaction during the time in the dining room, to encourage drinking (Cook *et al.*, 2019a; Lea *et al.*, 2017; Mentes *et al.*, 2006). In Cook *et al.* (2019a) staff considered the accessibility of drinks for older people; they recognised that it was important to have places where people could get drinks, regardless of mobility status, using 'hydration stations'. Some environmental strategies are dependent on the available resources.

2.8.5.6 Resources

One important resource is having a variety of drinks available on offer (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Mentes *et al.*, 2006; Wilson *et al.*, 2020). Having a variety of flavours, textures, temperatures and different coloured drinks was also important (Cook *et al.*, 2019a), while a range of cups and aids was also beneficial (Cook *et al.*, 2019a; Wilson *et al.*, 2020). The ability to monitor using fluid charts was also identified by staff in care homes (Godfrey *et al.*, 2012). The final strategy presents how relatives can assist with hydration care.

2.8.5.7 Relatives

Relatives' presence provided a range of support for hydration care. Having a carer present was felt to provide assistance, advocacy and facilitation of hydration for the older person (Bernoth *et al.*, 2014; Mentés *et al.*, 2006). Families were seen to assist by bringing in food and drinks, but beyond the products offered, the act of providing and sharing this was felt by staff to positively affect the mood of the older person (Mentés *et al.*, 2006). To encourage this care, staff may consciously involve the carer in the process of providing food and drink to the older person, so they can share that activity (Cook *et al.*, 2019a). As the carer knew the person best, they could also be a source of knowledge for the staff (Mentés *et al.*, 2006).

2.8.6 Barriers to hydration

Most of the barriers to hydration fit into the same categories as the strategies for hydration. Additionally, it may be that if the opposite of the strategies happens within the care settings this could become a barrier, however, only barriers identified specifically in the literature are presented here. There were two additional categories identified to add to the seven strategy categories: monitoring and individual. Table 2.4 sets out the barriers and associated studies.

Table 2.5: Barriers to hydration care from integrative literature review

| References | Approach | Assist | Monitoring | Communication | Individual | Environmental | Organisational | Relatives | Resources |
|--|----------|--------|------------|---------------|------------|---------------|----------------|-----------|-----------|
| (Armstrong-Esther <i>et al.</i> , 1996) | | | | | | | | | |
| (Beattie <i>et al.</i> , 2014a) | | | | | | | | | |
| (Chidester and Spangler, 1997) | | | | | | | | | |
| (Gaff <i>et al.</i> , 2015) | | | | | | | | | |
| (Jimoh <i>et al.</i> , 2019) | | | | | | | | | |
| (Namasivayam-MacDonald <i>et al.</i> , 2018) | | | | | | | | | |
| (Reed <i>et al.</i> , 2005) | | | | | | | | | |
| (Spangler and Chidester, 1998) | | | | | | | | | |
| (Cook <i>et al.</i> , 2019a) | | | | | ✓ | | | | |
| (Mentes, 2006) | | | | | | | | | |
| (Ullrich and McCutcheon, 2008) | | | | | | | ✓ | | |
| (Wilson <i>et al.</i> , 2020) | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | | ✓ |
| (Bernoth <i>et al.</i> , 2014) | ✓ | | | | | | ✓ | | ✓ |
| (Godfrey <i>et al.</i> , 2012) | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | | |
| (Lea <i>et al.</i> , 2017) | ✓ | | | ✓ | | | ✓ | | |
| (Lea <i>et al.</i> , 2019) | ✓ | ✓ | | ✓ | ✓ | | | | ✓ |
| (Mentes <i>et al.</i> , 2006b) | | | | | | | | | |

2.8.6.1 Approach

Staff approach could be detrimental to supporting hydration care, as explained by the relatives in Bernoth *et al.*'s. (2014) study; this could be traumatic for relatives to witness and be perceived as neglectful. An inadequate approach may include overestimating the aids a person requires or not providing a choice (Lea *et al.*, 2019). Even when a preference was taken into account, staff may disregard this based on their own views, such as the report that a staff member told a person tea was better for them than their preference of coffee (Wilson *et al.*, 2020). There were also difficulties in the way hydration care was balanced with other tasks such as washing or getting commodes, which could impact the experience (Godfrey *et al.*, 2012). Residents reported perceiving the staff as being too busy to ask them for a drink (Wilson *et al.*, 2020). Other issues related to providing drinks in dirty cups, not making the experience sociable, or not waking up people who are sleeping to offer them drinks between mealtimes (Bernoth *et al.*, 2014; Godfrey *et al.*, 2012; Wilson *et al.*, 2020). These aspects of the approach staff took, could lead to a diminished experience, or neglect of hydration for older people in care settings.

2.8.6.2 Assistance

Staff barriers relating to assistance were not indicated as frequently as the strategies staff employed to assist hydration. The documented barriers were staff not leaving cups within reach, not positioning people adequately for drinking or failing to recognise when a person was having difficulty with drinking (Bernoth *et al.*, 2014; Godfrey *et al.*, 2012; Lea *et al.*, 2019; Wilson *et al.*, 2020). Another staff action for hydration is monitoring hydration.

2.8.6.3 Monitoring

There were several barriers to effective monitoring described by Godfrey *et al.* (2012). These were that staff collected cups without checking with the person if they had finished or if they would like more drink, staff taking away cups without recording the intake, as well as observing staff completing fluid balance charts without knowing how the staff were aware of what the person has consumed.

2.8.6.4 Communication

The communication barriers were between staff and the older people, between staff and relatives or between staff and managers. A paucity of dialogue when offering or supporting hydration care was noted by Godfrey *et al.* (2012). Lea *et al.* (2019) found that when the OPLWD they were observing was provided with a drink, no staff verbally prompted her to drink it, whether in her own room or the dining room. Relatives within the hospital highlighted that they had not felt supported to provide hydration care as the types of fluid or volume of fluids that their relatives could consume had not been communicated to them (Godfrey *et al.*, 2012). Staff in the Lea *et al.* (2017) study felt disheartened by suggestions they had made to managers as they felt these were not listened to and no changes were made. As well as barriers within the influence of staff, there were individual barriers relating to the older person, which could be a barrier to the delivery of hydration care.

2.8.6.5 Individual

There were individual perceptions, situations and health issues which could be barriers to hydration care. The older person may not want to consume fluids, or refuse the fluids offered (Cook *et al.*, 2019a; Mentès *et al.*, 2006; Wilson *et al.*, 2020). They may lack the energy to drink, be asleep, forget to drink, or be distracted with

other occupations (Cook *et al.*, 2019a; Godfrey *et al.*, 2012). Within the study by Menten *et al.* (2006b) the staff attributed psychological factors as causes for individuals' low intake, such as stating people may be depressed, lonely or feel hopeless, linking emotional considerations to fluid intake. Another health factor considered detrimental to fluid intake was if a person had a swallowing problem (Menten *et al.*, 2006). Functional difficulties such as not being able to pick up the drink, or having dementia, were also considered to impact negatively on fluid intake (Cook *et al.*, 2019a; Menten *et al.*, 2006).

2.8.6.6 Organisational

Most of the organisational barriers identified in the literature demonstrated issues linked with routines, issues with staff-to-staff communication which were potentially compounded by the hierarchy of the care settings, or professionally distinct roles. The routinised approach and timing of the drink trolley did not suit all older people's needs (Godfrey *et al.*, 2012; Lea *et al.*, 2017; Wilson *et al.*, 2020). Staff also reported feeling they did not have enough time or sufficient staff to carry out all the care required (Godfrey *et al.*, 2012; Lea *et al.*, 2017). Management may not be aware of the day-to-day challenges, which could lead to staff not recognising how to influence change (Bernoth *et al.*, 2014; Lea *et al.*, 2017). Staff working part-time shift patterns were also considered to have a detrimental impact on the ability to influence change. Ullrich and McCutcheon (2008) found that the staff delivering the hydration care were not the staff who had read or written the care plans, which was echoed by the staff in the study by Lea *et al.* (2017) who indicated staff may only be aware of issues in their own, discrete areas.

2.8.6.7 Environmental

The environmental barrier relates to the rooms where older people had their drinks. Wilson *et al.*, (2020) found that residents in their own rooms did not receive a drink as often as those within the communal area.

2.8.6.8 Resources

Resources relates to choice, aids and the quality of products available. Godfrey *et al.* (2012) found that there was limited availability of drinking aids in both the care home and hospital setting. The choices were limited, or there was incorrect equipment to deliver drinks in keeping with preference, or to deliver drinks outside of the scheduled meals (Godfrey *et al.*, 2012; Wilson *et al.*, 2020). Relatives described the quality of food on offer as being inadequate, with soup described as cold and watery (Bernoth *et al.*, 2014). Relatives were viewed as hindering hydration care at times.

2.8.6.9 Relatives

In Menten *et al.* (2006) study, staff expressed relatives created barriers to hydration care if they did not provide sufficient support, or spend enough time with their relatives. One associated factor staff described was the detriment to the older person's mood when their relative does not spend much time with them, which staff felt reduced fluid intake.

2.9 Summary

Overall, this integrative literature review demonstrates that hydration is a complex aspect of care. However, the findings are strongly weighted to data from care home or nursing home settings, as this is where most studies were conducted. The limited

data from hospitals indicates that this is likely to be the case in hospital settings also (Gaff *et al.*, 2015; Godfrey *et al.*, 2012). However, there is a gap in the knowledge detailing the specific complexities of hydration care within the hospital setting, therefore further investigation of hydration care within a hospital setting is needed. As organisation and environment contribute to the complex factors influencing hydration care, and hospitals are organisationally and environmentally different to long-term care settings, there may be unique factors which impact on hydration care. However, most research included in this review does not explicitly identify the organisational contexts, so this is a gap in knowledge.

The quantitative data particularly, demonstrates that older people across demographics and categorisations in care settings regularly consume lower than recommended amounts of fluid. The mixed methods and qualitative data elicit some of the multifactorial reasons for this. Beyond intake, the evidence demonstrates that hydration has relevance beyond clinical care and the process of hydration can influence the psychological and social aspects of care for the individual older person, as well as affecting the emotions of their relatives. This supports the view that every older person will require individual assessment, care and support to determine their intake and meet their individual needs to promote biopsychosocial health and wellbeing. This fits with a person-centred approach to care. However, PCC was only commented on by Lea *et al.* (2017) within the literature identified; they concluded that there was reduced awareness about effective care practices such as PCC which impacts food and fluid intake. The limited discussion of PCC within the hydration literature demonstrates that discussions of a PCC approach to hydration care are missing from the available evidence base on this topic. Other authors completing literature reviews regarding interventions to aid hydration or

reduce dehydration for long-term care residents also concluded a person-centred approach is required (Bunn *et al.*, 2015; Cook *et al.*, 2019b). However, none of these three papers, which discussed PCC alongside the topic of hydration, have defined their meaning of PCC or explicitly stated what person-centred hydration care is (Bunn *et al.*, 2015; Cook *et al.*, 2019b; Lea *et al.*, 2017) . Therefore, what person-centred hydration care looks like in an acute hospital, and what is required for this to be achieved, is still unclear and requires further exploration.

Additionally, the evidence suggests that beverage delivery within care settings is routinised and the staff approach when offering drinks is not widely reported in these pieces of research. The limited evidence suggests that social interactions are reduced during drink delivery, so this does pose questions about how this impacts the required, person-centred approach to hydration care. Therefore, future research should examine the interactions between staff and OPLWD when delivering hydration care and ways these can provide successful hydration care.

The evidence suggests there are multiple staff roles involved in hydration care but understanding these could be expanded through further research to clarify the range and nature of roles involved. Additionally, carers have a role within hydration care but their views and the views of older people remain underexplored within the literature. Further research which provides evidence about the range of roles in hydration care, including the carers and the older person's views, would address these knowledge gaps.

Strategies and barriers to hydration care were identified through this literature, which indicates there are aspects of hydration care which could be developed to improve care. However, as most studies which reported strategies and barriers were in long-

term care settings, it would be beneficial to elicit specific strategies and barriers within an acute hospital setting. The studies which were able to capture many of the complexities of hydration care were those utilising multiple data collection methods, especially when presenting qualitative data which examined the range of factors influencing care and a variety of views (Godfrey *et al.*, 2012; Lea *et al.*, 2017, 2019; Mendes *et al.*, 2006; Wilson *et al.*, 2020).

Additionally, most of the studies report data about older people's care, not OPLWD, and it would be beneficial to focus on the population of OPLWD, who have unique needs within an acute hospital.

The research aims and questions developed from this literature review are presented next.

2.10 Research aim

Based on the gaps identified through the integrative literature review, the aim of this research is to use the concept of person-centred care to explore and describe the factors influencing hydration care and the associated experiences of OPLWD in acute hospitals.

As PCC is an aspect integral to the research aim, it was necessary to further explore and define the concept of PCC. Therefore, chapter three provides a conceptual framework of PCC, which contributed to developing the research objectives, questions and the methodology required to explore hydration care for OPLWD within acute hospitals using the concept of PCC.

2.11 Chapter summary

This chapter further explored the topic of hydration for older people in care settings through an integrative literature review which explored primary research about hydration care for older people in care settings. The findings demonstrate that there are complex, multifaceted aspects which could affect an older person's actual fluid intake and the related experience of hydration. The findings suggest that hydration care is not a simple aspect of care and strategies and barriers to hydration care are identified through the literature review. Whilst the literature provided information about this topic, there were gaps identified: such as, a lack of data from hospital settings, limited focus on OPLWD, little data incorporating carers' views, or studies which utilised the concept of PCC. The chapter concluded by introducing the research aim. The next chapter will explore the concept of PCC further and how this is currently carried out within acute hospital settings, concluding with the research questions. The intention of the next chapter is to provide a conceptual framework to support the research methodology, discussed in chapter four.

3 Person-centred care

3.1 Introduction

This chapter explores the concept of person-centred care (PCC) as it relates to dementia care, commencing by explaining that there is no one definition of PCC. The ideas related to PCC for people with living dementia (PLWD) are introduced through the work of Tom Kitwood (Kitwood, 1997), who discussed the terms personhood, malignant social psychology and positive person work within dementia care. Physical health, and the relationship this has to PCC is then explored. Several frameworks which define PCC are introduced and then the use of the VIPS Framework (Brooker and Latham, 2016) is justified. Finally, the literature considering how PCC is applied to the care of PLWD who are being treated in hospitals is presented through an umbrella review.

3.2 Person-centred care

PCC is often considered the optimal approach to care, particularly for older people and those with dementia (Edvardsson *et al.*, 2010; NICE, 2018; Slater *et al.*, 2015). The approach is widely discussed in books, policies and research globally, but lacks a universal definition (Brooker, 2003; Kogan *et al.*, 2016; Morgan and Yoder, 2012).

Although Kitwood is credited with bringing the concept of PCC to the field of dementia care (Brooker, 2003), PCC was already in use within therapy, attributed to the work of Carl Roger. Rogers (1951) developed the humanistic approach to psychotherapy; client-centred therapy which focuses on understanding an experience from the person's perspective. Kitwood's concept was constructed over

several scholarly works (Kitwood, 1990, 1993; Kitwood and Bredin, 1992b). Although his methods have been criticised as lacking rigour due to limited description of his approaches (Adams, 1996; Dewing, 2004), there has been wide uptake of PCC as an approach to caring for PLWD. Kitwood's work was underpinned by the principles of personhood and what he termed malignant social psychology and positive person work which are explored further in the next sections.

Kitwood's aim was to develop an alternative to what he identified as 'the standard paradigm,' which was the medicalised model or the 'old culture' of dementia care (Kitwood, 1997 p. 135). He explained that in the old culture, the disease is considered first, with measures of decline monitored; consequently, the PLWD is secondary to the dementia disease. He expressed the old from the new in this way: "our frame of reference should no longer be person-with-DEMENTIA, but PERSON-with-dementia" (Kitwood, 1997, p. 7). The focus on the person forces a consideration of what it is to be a person; this is structured around the concept of personhood which will be discussed in 3.2.1.

3.2.1 Personhood

Personhood, as a concept, seeks to define the attributes that make a human being a person (Dewing, 2008). This is a wide-reaching philosophical question that is open to debate. The responses have implications for legislation (Foster and Herring, 2017), ethics (Merrill, 1998), theology (White, 2013) and care (Dewing, 2008). Kitwood's definition is: "A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997 p. 8). He advocates a personhood defined by the importance of relationships and related to the uniqueness and value

of a person. The concept of personhood within healthcare, when defined as 'a status' has been critiqued. The assigning of criteria to be classed as a person has the potential that not all humans gain or maintain that status, leading Dewing (2008) to question the prominence personhood has in theories of nursing older people. Despite potential critique, other authors presenting theories for nursing older adults also engage in discussion about the importance of considering personhood (Nolan *et al.*, 2004). In Kitwood's definition, relationships promote personhood but he identifies a range of approaches to interactions that can undermine personhood. He calls this malignant social psychology (Kitwood, 1990), which is discussed in the next section.

3.2.2 Malignant social psychology

Malignant social psychology is the term used for the range of interactions that undermine personhood (Brooker and Latham, 2016; Kitwood, 1990, 1997). Kitwood (1997) was clear that these aspects of care are not the fault of individual staff members but fostered by the culture and environment that care takes place in. The types of interaction that fall into malignant social psychology are presented in table 3.1.

Table 3.1: Malignant social psychology categories

Adapted from (Kitwood, 1997, pp. 46–47)

| Malignant Social Psychology Category | Description |
|---|---|
| Treachery | When deception is used to force compliance. |
| Disempowerment | Restricting a person’s abilities. |
| Infantilisation | Patronising a person. |
| Labelling | Using a label, such as dementia, as the main way for explaining a person’s behaviour. |
| Stigmatisation | Objectifying the person through their diagnosis. |
| Outpacing | Putting the person under pressure to make choices or engaging in a manner that is too fast for them. |
| Invalidation | Not taking account of the person’s subjective experience and how they feel. |
| Banishment | Physically or psychologically excluding a person. |
| Objectification | Doing things to a person without considering that they are a person with emotions and feelings. |
| Ignoring | Acting or conversing around the person as if they are not there. |
| Imposition | Forcing a person to do something or denying them a choice. |
| Withholding | Not meeting a clear need or denying interaction when the person expresses a desire for acknowledgement. |
| Accusation | Blaming a person if their lack of ability or understanding impacts a situation. |
| Disruption | Suddenly intruding on or disturbing the person’s action or engagement. |
| Mockery | Humiliating the person or joking at their expense. |
| Disparagement | Damaging a person’s self-esteem through messages or telling them they are worthless, useless etc. |

Counteracting malignant social psychology involves engaging in positive person work. This will be discussed next.

3.2.3 Positive person work

Positive person work counters malignant social psychology and is facilitated through interactions, which take account of the PLWD's individuality, needs and abilities (Kitwood, 1997). The importance of communication to PCC led to Kitwood identifying that to understand dementia care, it was essential to observe interactions. He created the use of Dementia Care Mapping (Kitwood and Bredin, 1992a) but also identified observational methods such as the Quality of Interaction Schedule (QUIS) (Dean *et al.*, 1993) as useful. The QUIS is discussed in the methodology chapter section 4.7.3. Kitwood (1997) felt the theories on positive person work still required further research but unfortunately, he did not get a chance to develop these in his lifetime, dying shortly after the publication of his book. The interactions he identified as positive person-work are documented within table 3.2.

Table 3.2: Positive person-work categories and description

Adapted from (Kitwood, 1997, pp. 90–91)

| Positive person work categories | Description |
|---------------------------------|---|
| Recognition | Acknowledging the person through use of their name, words, listening or eye contact. |
| Negotiation | Engaging the person about their needs and preferences, empowering them in their care. |
| Collaboration | Working with someone, facilitating care, working with the person and their abilities, not doing things to them. |
| Play | Engaging in something where there is no goal other than the activity itself, as opposed to work, creating a moment for self-expression. |
| Timalation | Interactions that involve the senses. |
| Celebration | Sharing joy, not just on special occasions. |
| Relaxation | People working with the PLWD, relaxing in their presence, which may aid the PLWD to relax. |
| Validation | Empathising with the person, to acknowledge their emotions, feelings, and their own experience. |
| Holding | Mostly related to psychological holding, although physical holding may be required. |
| Facilitation | Collaborating to fill in the parts of an action that a person cannot do alone. |

As positive person work is provided through interactions, and interactions are influenced by the context and environment, these aspects can be seen as being part of the social environment (Brooker and Latham, 2016). Kitwood (1997) also raised

that psychological care could not be provided without regard for physical care, which is explored in the next section.

3.2.4 Physical health

Kitwood's theory of PCC focusses on interactions, promoting psychological aspects of care but Kitwood (1997) advocated against the separation of the mind from the body and influenced his perspective on the importance of physical health. He outlined that meeting a person's physical health needs is a vital part of providing PCC, warning against assuming a psychological-only cause for an issue and neglecting a potential physical cause (Kitwood, 1997, p. 34). He discussed the negative impact that delirium, pain and sensory impairments such as hearing can have on the person, further supporting the view that PCC is a biopsychosocial approach to dementia care. Since Kitwood's work, other scholars have advanced the theory of PCC. The person most closely following on from Kitwood's foundation is Dawn Brooker, through the development of the 'VIPS Framework' (Brooker and Latham, 2016). This will be discussed next, along with other frameworks for PCC.

3.2.5 The VIPS Framework of person-centred care

PCC is seen as key to providing optimal care to people living with dementia in all settings (NICE, 2018), including within acute hospitals (James *et al.*, 2017). The theoretical work on PCC has been developed by academics since Kitwood (Kitwood, 1997) and practice frameworks have been developed such as the VIPS Framework (Brooker, 2003) the Senses Framework (Nolan *et al.*, 2004) and the Person-centred Nursing Framework (McCormack and McCance, 2006) or the Person-centred Practice Framework (McCormack and McCance, 2010). Of these, only the VIPS framework has been developed specifically to consider the health and social care

provided for people with dementia. The VIPS framework provides a four-part definition of PCC for PLWD:

Valuing people: A value base that asserts the absolute value of all human lives regardless of age or cognitive ability.

Individual lives: An individualised approach, recognising uniqueness.

Personal perspectives: Understanding the world from the perspective of the person identified as needing support.

Social environment: Providing a social environment that supports psychological need” (Brooker and Latham, 2016, p. 12).

Brooker explains that some definitions of PCC focus on only one of these aspects; she counters that all parts must be present, they work in partnership, and one part is not more important than the other (Brooker, 2003). The four parts are now explored in more detail, with the indicators for how they can be demonstrated in practice, which are documented in table 3.3.

Table 3.3: VIPS Framework with indicators

Adapted from Brooker and Latham (2016, pp. 53–162)

| VIPS Framework definition | Explanation of the VIPS Framework definition | Indicators | Further explanation of the part of the definition and indicators for demonstrating them in care environments |
|---------------------------|--|--|--|
| Valuing people | A value base that asserts the absolute value of all human lives regardless of age or cognitive ability | <ul style="list-style-type: none"> • Vision • Human resources • Management ethos • Training and staff development • Service environments • Quality assurance | <p>This involves valuing PLWD and the staff caring for them. Everyone should know what the organisation stands for and staff should know their value. Management empowers staff to provide direct care that is person-centred. Caring for PLWD is seen as skilled and important, the workforce is developed to provide PCC. The physical and social environment supports PLWD. PLWD and their relatives contribute to quality improvement.</p> |
| Individual lives | An individualised approach, recognising uniqueness | <ul style="list-style-type: none"> • Care and support plans • Regular reviews • Personal possessions • Individual preferences • Life story • Activity and occupation | <p>This involves seeing people as individuals with a life history and unique personality. This should be reflected in care and support plans, including strengths and needs. Regular reviews recognise that people can change. People have their own items and staff know about these items. A person's preferences are known and acted on. The important relationships and key events in the person's life are known by the staff. A person is encouraged to be active and engage, regardless of their need or abilities.</p> |

| VIPS Framework definition | Explanation of the VIPS Framework definition | Indicators | Further explanation of the part of the definition and indicators for demonstrating them in care environments |
|------------------------------|---|--|---|
| Personal perspectives | Understanding the world from the perspective of the person identified as needing support. | <ul style="list-style-type: none"> • Communication is key • Empathy and acceptable risk • Physical environment • Physical health • Challenging behaviour as communication • Advocacy | <p>This involves recognising that the PLWD has their own valid, perspective on the world and empathy is shown that this is where the person is acting from.</p> <p>All forms of communication are valid and responded to. Behavioural communication is seen as a form of expression to be engaged with not managed. Staff attempt to view the PLWD's point of view. The physical environment helps someone feel safe and comfortable. Physical health is monitored and optimised. Staff advocate for the respect and dignity of the PLWD.</p> |
| Social environment | Providing a social environment that supports psychological need. | <ul style="list-style-type: none"> • Inclusion • Respect • Warmth • Validation • Enabling • Part of the community • Relationships | <p>This involves a recognition that relationships are part of being a person. The environment provides opportunities for the PLWD to engage and compensates for their impairments. PLWD are included in what is happening. The support that is provided respects the individual's strengths and needs. Warmth is demonstrated through acceptance and welcoming. PLWD's emotions are responded to. People participate as partners in their care. The people important to the PLWD are known and welcomed. A connection with the community is encouraged.</p> |

Whilst the VIPS Framework is built on the foundations of Kitwood's model it does progress some aspects which others have critiqued Kitwood for not addressing, including the context or organisational aspects of care and allowing for the needs of relatives and staff (Dewing, 2008). The VIPS framework is not the only framework for PCC (Dewing, 2004), however, it is the definition within the guidelines for dementia care within the UK (National Institute for Health and Care Excellence, 2018) (presented in section 1.5). As my research is based in the UK and relates to current practice, the use of this definition aligns the thesis with the policy framework during the period this research took place. One limitation of the VIPS Framework is that it is used most widely in care homes. However, the model has been used to frame discussions on PCC in acute hospitals within the literature (Houghton *et al.*, 2016). Alternative frameworks and models applicable to PCC will be explored next.

3.2.6 Alternative approaches

There are other approaches to defining PCC or frameworks to apply to care for older people or PLWD. Another framework related to PCC is the "Person-centred nursing framework" (PCNF) (McCormack and McCance, 2006). This was developed from work on the conception of older people's nursing (McCormack, 2003) and work on caring in nursing (McCance *et al.*, 2001). Notably, it was developed from research conducted in hospitals, however there is a limitation as it focusses on the role of the nurse (McCormack, 2020; McCormack and McCance, 2006). The framework has adapted to integrate an interprofessional approach which is termed the "Person-Centred Practice Framework" (PCPF) (McCormack and McCance, 2017), although the focus remains a nursing theory (McCormack, 2020). The PCNF has four parts:

1. "Prerequisites focus on the attributes of the nurse.
2. "The care environment focuses on the context in which care is delivered.

3. "Person-centred processes focus on delivering care through a range of activities.
4. Expected outcome is the result of effective person-centred nursing."
(McCormack, 2020, p. 475)

The VIPS Framework and PCNF have overarching themes which are recognisable in both frameworks, such as, the importance of relationships, defining what it is to be a person, recognising the context in which care takes place is an important influencer of care, and valuing the person receiving care as well as the staff.

Another framework often discussed when considering the implementation of PCC for older people's care is the Senses Framework (Nolan *et al.*, 2004), later defined as: a relationship-centred approach (Nolan *et al.*, 2006). The relationship-centred approach was considered an alternative to person-centred approaches (Nolan *et al.*, 2004). The Senses Framework, VIPS and PNF were all in development while PCC was highlighted as a priority by the National Service Framework (NSF) for Older People (DH, 2001) in the UK. The NSF asserted PCC was a priority and a way to improve services. McCormack and Nolan both critique aspects of PCC, however the VIPS Framework does counter some of the critiques levelled. Nolan *et al.*'s (2004) critique of PCC is derived from the definition of PCC which is used within the NSF for Older People (DH, 2001). The NSF portrayed a narrow view of PCC, equating PCC with individualised care, enabling people to make choices about their care and providing care based on their needs (DH, 2001). The critique was that this was based too much on individualism, autonomy, and independence, without reflecting the experience that older people have (Nolan *et al.*, 2004). The Senses Framework has similarities to other definitions of PCC, namely, the importance of relationships. The Senses Framework asserts relationships between the person receiving care, their family and the healthcare team are important, but also

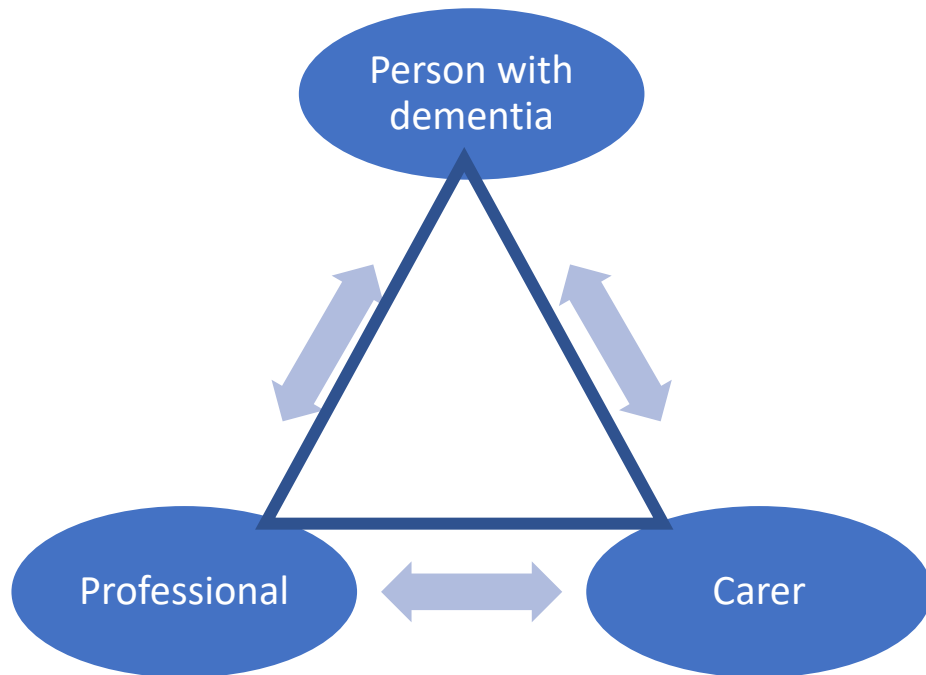
emphasises that the relationships within and between team members are also extremely important (Nolan *et al.*, 2004).

The Senses Framework regards personhood as important but places the emphasis on the interconnectedness of social relationships to personhood, a view shared with McCormack (2001). One critique of all the frameworks is that although they are underpinned by the importance of relationships, they do not explicitly state how to link the day-to-day interventions that practitioners perform to the relationships (Dewing, 2004).

Another approach highlighting the importance of relationships beyond that of the PLWD and the staff member was developed in the UK through a collaboration with the Royal College of Nursing and the Carers Trust. This is called the Triangle of Care for dementia (Carers Trust, 2012) (see Figure 3.1). Originally, The Triangle of Care was developed for use in mental health settings (Carers Trust, 2013) but the model was later adapted for use in dementia care, particularly focussed on acute hospitals (Carers Trust, 2012).

The triangle of care has six key standards, focussed on: identifying carers at first contact or soon after; training staff in carer engagement strategies; putting policies in place regarding sharing information; having defined posts with responsibility for carers; providing a carer introduction to the service and staff available; providing a range of carer support services (Carers Trust, 2012).

Figure 3.1: Triangle of Care



Adapted from (Carers Trust, 2012, p. 6)

Within this thesis, I have decided to use the term 'relative' rather than carer to identify any family or friends who act as a 'carer' for an OPLWD. This is to provide a clear distinction from any paid carers within the care settings discussed through this thesis.

Whilst the presence of multiple approaches to older people's and dementia care poses a challenge when choosing the 'right' definition to use within research, it would be problematic to not use a definition. To conduct research without a clear definition of PCC does not advance the understanding and development of person-centred practice (McCormack, 2020). Although the VIPS Framework is used as the definition in this research, the other frameworks and approaches to care have been considered. Regardless of the definition used, the frameworks described have some similarities and recognise the importance of relationships between professionals,

the PLWD and their relatives. The frameworks provide a basis for considering the theoretical underpinnings of the concept of PCC but incorporating the frameworks into practice is vital to the delivery of PCC in a real-world setting. In the next section, an umbrella review of research that investigated how PCC is currently delivered in acute hospital settings, will be presented.

3.3 Person-centred care for people living with dementia in hospitals: An umbrella review

A preliminary search of the literature about PCC for PLWD in acute hospitals identified recent literature reviews which synthesised relevant evidence from a variety of perspectives (Dewing and Dijk, 2016; Houghton *et al.*, 2016; Reilly and Houghton, 2019). Based on this, undertaking a literature review with a similar focus was not felt necessary, therefore an umbrella review was conducted to further the knowledge for this topic. No existing umbrella reviews on this topic were identified.

An umbrella review is an emerging methodology using existing reviews on a topic to incorporate findings into one document (Wiechula *et al.*, 2016). The need for this methodology has been recognised, particularly within healthcare due to an increasing number of reviews being published on healthcare topics (Hunt *et al.*, 2018; The Joanna Briggs Institute [JBI], 2014). Some papers describe this method as a way of providing an overview of quantitative systematic literature reviews or meta-analysis (Fusar-Poli and Radua, 2018). However, evolving methodologies enable existing quantitative and qualitative reviews to be used in umbrella reviews (Aromataris *et al.*, 2015; The Joanna Briggs Institute, 2014).

The methodology developed by the Joanna Briggs Institute (2014) to conduct umbrella reviews was used to inform the process.

3.3.1 Search methods, quality appraisal and data abstraction

A search was completed to answer the question: what is the evidence about person-centred care for people living with dementia in acute hospitals?

The databases searched were Medline, CINAHL, British Nursing Index, AMED, Epistemonikos and COCHRANE. Handsearching of all articles included for full text review was also completed. The date range was January 1990- January 2021. The search identified any of the key-terms below found in any part of the text:

Alzheimer* OR "cognitive deficit*" OR "cognitive dysfunction" OR "cognitive impairment" OR "cognitively impaired" OR dement* OR "memory impairment" OR "memory problem" OR "neurocognitive disorder*" OR psychogeriatric

AND

"person-centred care" OR "person centred care" OR "person-centered care" OR "person centered care" OR "relationship-centred care" OR "relationship centred care" OR "relationship-centered care" OR "relationship centered care".

AND

hospital OR "acute care" OR "acute setting" OR "acute hospital" OR inpatient OR "in patient" OR ward OR "healthcare environment" OR "health care environment."

The use of inclusion and exclusion criteria was used to guide the search.

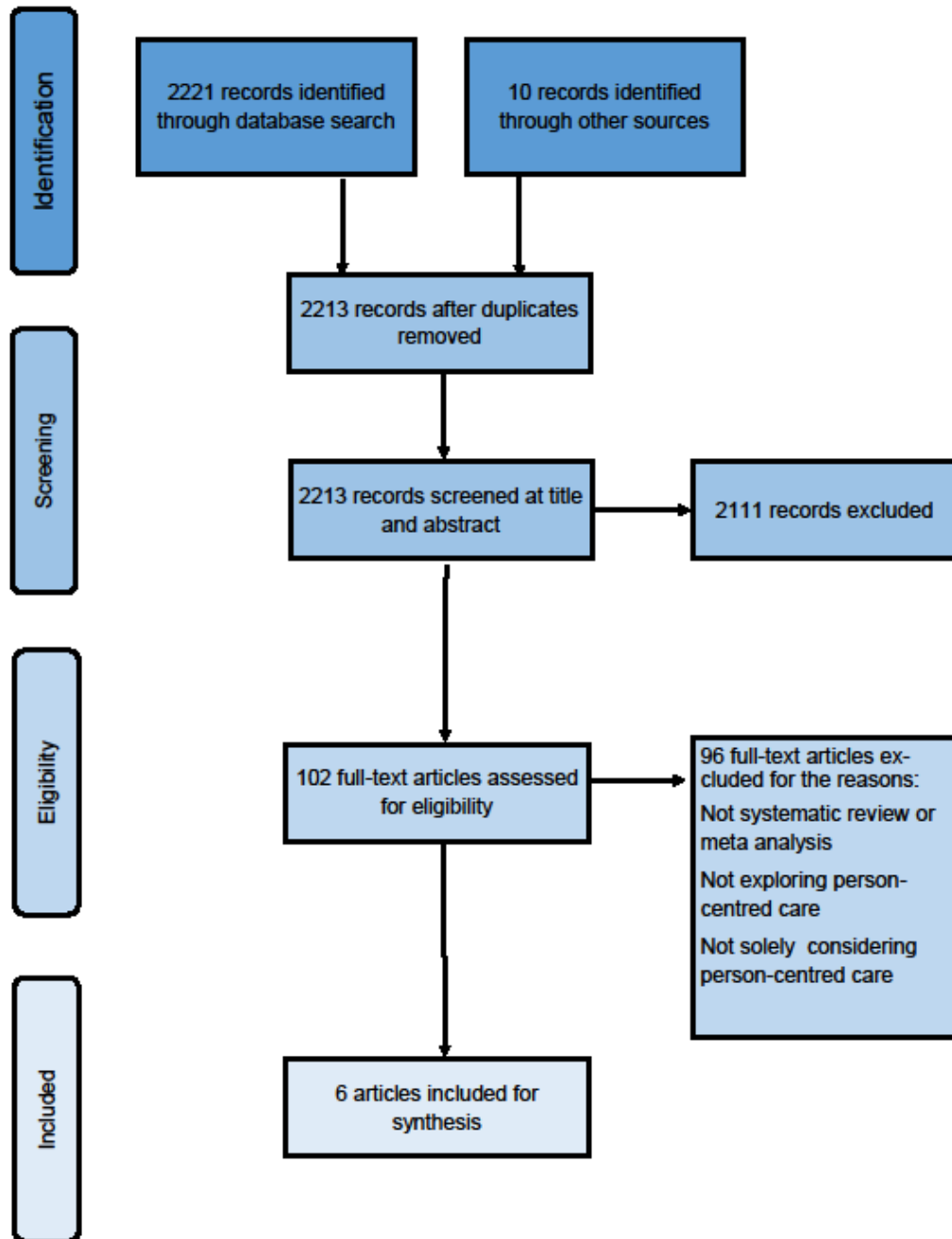
The search protocol required inclusion and exclusion criteria to guide the search, see table 3. 4.

Table 3.4 Person-centred care umbrella review inclusion and exclusion criteria

| Inclusion | Exclusion |
|--|--|
| Participants are people living with dementia, staff, or carers | Reviews with theoretical studies or opinion texts as primary sources |
| PCC is the focus of the review or the theory the review is framed by | Reviews are about the care for people who do not have dementia, or combine evidence about the care of people who do not have dementia with evidence about those who are living with dementia |
| The setting is a hospital | Includes settings other than hospitals |
| Systematic review, meta- analysis and literature reviews | |
| Meets at least 50% of the criteria on the JBI critical appraisal checklist for systematic reviews and research synthesis (Joanna Briggs Institution, 2020) | |
| Published in English language | |

The search results are displayed in a PRISMA diagram (Moher *et al.*, 2009), see figure 3.2.

Figure 3.2 Person-centred care umbrella review PRISMA diagram

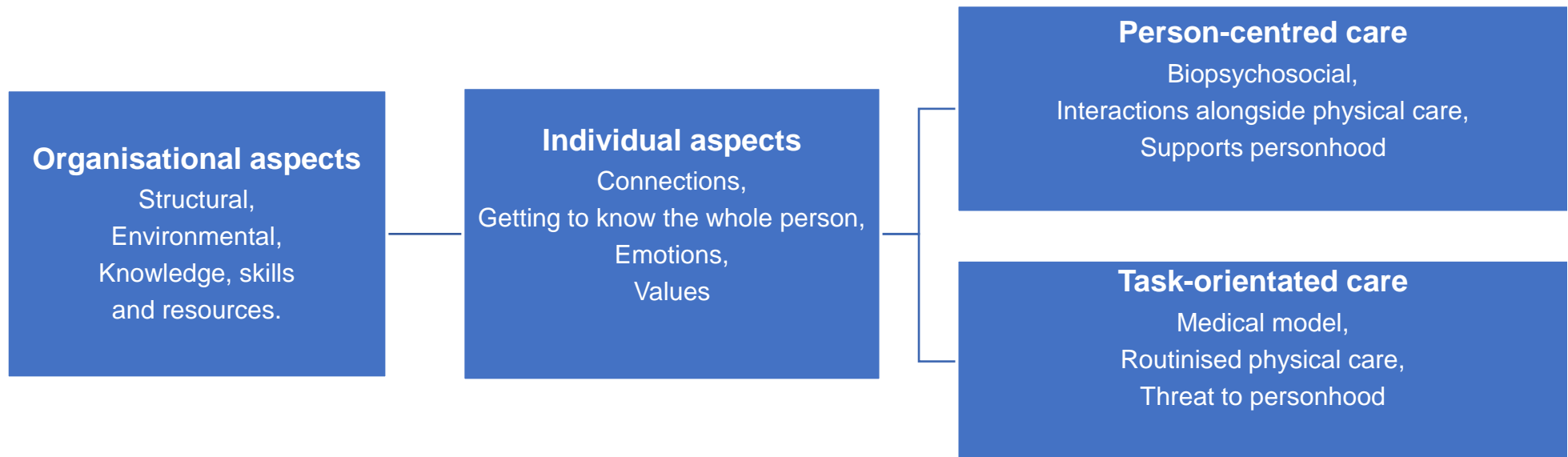


Once the literature reviews which met the inclusions criteria were identified, they were subject to quality appraisal and data abstraction. Extraction was undertaken using the JBI Data Extraction Form for Review of Systematic Reviews and Research Synthesis (The Joanna Briggs Institute, 2014, p. 34), a copy is provided in appendix four. Appraisal was conducted using the JBI Critical Appraisal Checklist for Systematic Reviews and Research Syntheses (The Joanna Briggs Institute, 2014, p. 29), the results of this can be found in appendix five. Umbrella reviews do not further synthesise results from other reviews, instead the aim is to present a summarised overview of the findings (The Joanna Briggs Institute, 2014).

The format for familiarisation followed a similar process to the umbrella review completed by Wiechula *et al.* (2016). To gain an overview of the literature reviews I read and re-read them to facilitate familiarity. Next, I produced a table displaying the reference, the findings, and a brief description of the findings, see appendix six. All the reviews found for the umbrella review had results separated by themes, so these themes were added verbatim to the table, the descriptions were paraphrased. Once all the themes and descriptions had been added they were re-read. A second table was created to begin combining similar themes from across the reviews into categories and subcategories, see appendix seven.

The results of the umbrella review are presented as two categories: Organisational factors and individual factors, with seven subcategories. The themes and subcategories are a synthesis, representing facilitators and barriers to PCC for PLWD in hospitals; if PCC is not facilitated the outcome of care is task-orientated care, see figure 3.3.

Figure 3.3: Barriers and facilitators to person-centred care for people living with dementia admitted to hospitals



3.3.2 Results

Two reviews were the experiences of hospital staff (Gwernan-Jones *et al.*, 2020; Houghton *et al.*, 2016), one was the views of nursing staff only (Brossard Saxell *et al.*, 2019), another provided the perspective of PLWD (Reilly and Houghton, 2019). Two reviews captured the perspectives of staff, PLWD and their relatives (Brooke and Ojo, 2018; Dewing and Dijk, 2016). Four of the reviews used qualitative evidence (Brossard Saxell *et al.*, 2019; Gwernan-Jones *et al.*, 2020; Houghton *et al.*, 2016; Reilly and Houghton, 2019) and two used a range of qualitative, quantitative, and mixed methods studies (Brooke and Ojo, 2018; Dewing and Dijk, 2016). The reviews defined person-centred care using Kitwood (Brossard Saxell *et al.*, 2019; Gwernan-Jones *et al.*, 2020), a combination of Kitwood and VIPS Framework (Reilly and Houghton, 2019), a combination of VIPS Framework and the PCNF (Houghton *et al.*, 2016) or did not use a specific definition (Brooke and Ojo, 2018; Dewing and Dijk, 2016).

3.3.3 Findings

The overall finding of the umbrella review was: person-centred dementia care within hospitals remains in flux. PCC is the method of care that supports a PLWD's biopsychosocial needs and improves the experience of hospital care for PLWD, staff and their relatives. Currently, the pressure to meet the needs of PLWD by providing PCC falls on staff. The barriers and facilitators to PCC are multifaceted and reliant on organisational as well as individual factors. The onus to facilitate PCC cannot be supported solely by the attributes of individual staff members. These aspects will

now be discussed, including the impact they have on the experience of staff, PLWD and their relatives.

3.3.3.1 Organisational Factors

Organisational factors impact on the experience of PLWD, their relatives, and hospital staff because they are barriers or facilitators to PCC. These aspects fit into three subthemes: structural, environmental and knowledge, skills and resources.

3.3.3.1.1 Structural

The structural factors relate to the philosophies of care within the hospital, the priorities of the service and the impact this has on how staff approach care, which influences the experience of hospital care for all involved. Wards were found to be routinised and task-focussed, specifically on acute or physical care. Task-focussed care was felt to fit into a medical-model and hampered delivery of PCC (Reilly and Houghton, 2019) (Finding 1a).

The task-driven routines, coupled with a focus on compliance targets and safety could lead to the PLWD becoming viewed as “objects of care” (Dewing and Dijk, 2016, p. 6) (Finding 1j). A focus on safety was noted, which impacted on physical care as well as PCC (Houghton *et al.*, 2016) (Finding 1g). There was the possibility for nurses to deviate from the routines which hindered PCC, although there was not a consensus about this approach, as other nurses felt routines provided security and control (Brossard Saxell *et al.*, 2019, pp. 16–17) (Finding 1e).

Being with the person and providing the time and space for psychosocial care was considered a luxury (Houghton *et al.*, 2016) and opportunities to provide PCC were missed (Dewing and Dijk, 2016). There was a suggestion that the organisational

leadership may underestimate the complexity and time that is involved when providing care to PLWD (Dewing and Dijk, 2016). Nurses suggested that when they were able to collaborate with colleagues, prioritise interactions above other tasks and had supportive leaders who were involved in care for PLWD; this was beneficial to providing care for PLWD (Brossard Saxell *et al.*, 2019, pp. 14–15) (Finding 1d).

Sharing knowledge was not easy to achieve consistently because information sharing systems were unclear, not in place at all or hierarchical issues meant that the staff who had the most contact with PLWD were not empowered to share this knowledge; this could happen across and within roles (Gwernan-Jones *et al.*, 2020, p. 10).

Sharing information and getting to know the person was key to being able to provide PCC. Overall, the structures of the hospital affected staff ability to carry out this type of care and there were many examples of how the focus on tasks, routines and safety were given priority over PCC. Despite this, hospital staff are able to find ways to provide PCC, however evidence suggests this may be contrary to typical practice and can impact on the emotions of the staff, which is discussed in 3.3.3.2.3. As well as the structural aspects, environmental aspects influence care delivery, these are discussed next.

3.3.3.1.2 Environmental

The physical environment of the ward was perceived by PLWD and staff as being unsuitable. This was due to issues such as the ward being too busy, lacking privacy, having a poor layout, and being disorientating; potentially adding to the PLWD's confusion and anxiety (Houghton *et al.*, 2016, p. 113) (Finding 3d).

With limitations, detrimental environmental features could be adapted to enhance the space, by improving signage, lighting, adding personal items and increasing purposeful activities to make it more homely and comforting to PLWD and improve relative's perceptions of care (Dewing and Dijk, 2016, p. 5) (Finding 3e).

In addition to environmental difficulties, the PLWD were also coping with disruptions to their usual routine; without adaptations there was a risk that PLWD would experience negative psychological consequences such as boredom, lack of control and a loss of freedom and unnecessary restrictions on their movements (Reilly and Houghton, 2019). The physical environment influenced the physical constraints and psychological perceptions of PLWD but some of the challenges to providing PCC could be resolved through some adaptations. However, interactions and care approach influence the environment and the presence of staff, who are part of the environment, could reduce the anxiety that PLWD felt (Dewing and Dijk, 2016, p. 5). The environmental adaptations which may facilitate wellbeing for PLWD were in conflict with the medicalised nature of the wards, and issues such as competing for space with medical equipment and concerns about infection control could impact the ease of adapting the environment (Houghton *et al.*, 2016, p. 112). In a similar way to the structural findings, facilitating environmental adaptations required action from individual staff, which potentially relies on their confidence, their knowledge, and their skills, which are discussed next.

3.3.3.1.3 Knowledge, skills and resources

Staff possessing theoretical and practical knowledge was important for staff and expected by PLWD and their relatives, to facilitate complex communication and care delivery (Brooke and Ojo, 2018; Gwernan-Jones *et al.*, 2020). Despite the

importance of this knowledge it is not consistently acquired and staff do not feel they have the necessary skills (Houghton *et al.*, 2016). There are organisational barriers and challenges related to acquiring formal knowledge, (Houghton *et al.*, 2016) and further complications due to insufficient evidence about the optimal formal dementia training (Brooke and Ojo, 2018; Dewing and Dijk, 2016). Nurses reported that professional and personal skills, knowledge, and experience benefited their care delivery, improving how they relate to, understand and care for PLWD (Brossard Saxell *et al.*, 2019, p. 12) (Finding 2e). Without an ability to interpret the PLWD's behaviour and adapt care accordingly, staff were more likely to attempt to fit the PLWD into the medical model (Gwernan-Jones *et al.*, 2020). Evaluations of formal training suggested some positive outcomes, such as improved dementia awareness, staff perceptions and attitudes, confidence providing care, clinical and assessment skills, awareness of pain and less sedatives, improving the patient experience (Dewing and Dijk, 2016, p. 13) (Finding 2c).

Despite the potential benefits, achieving attendance to training programmes could be a challenge (Brooke and Ojo, 2018). Further, without organisational support, being able to implement ideas from training comes with challenges, as the current hospital structure has competing priorities and a focus on compliance targets (Dewing and Dijk, 2016), discussed in section 3.3.3.1.. The need for solutions which consider the complexities of implementing change in dementia care was felt to require more than a well-meaning workforce, it also required education and training to support skilled communication simultaneously alongside constructing supportive organisational structures, managers, and colleagues. (Brooke and Ojo, 2018, pp. 12-19) (Finding 2e).

The use of volunteers, specialist nurses and the development of specialist units were highlighted in the reviews as potentially positive but all lacked evidence about their impact on key outcomes (Brooke and Ojo, 2018), particularly specialist nurses and mental health liaison teams (Dewing and Dijk, 2016). This section highlights the variety of organisational aspects that influence the delivery of PCC. There are challenges to achieving PCC due to the medicalised model, routines, and priorities that hospitals value. The findings indicate that within the organisational limitations, individual actions can still influence care delivery, individual factors are discussed next.

3.3.3.2 Individual Factors

Individual factors relate to the PLWD, their relatives and the staff, who all have a place within the organisation. There are four subcategories: Connections, Getting to know the person, Emotions and Values. Connections illustrates how interactions between PLWD and staff can facilitate or be a barrier to PCC, this is linked to interactions in the moment. Getting to know the person is also about interactions, however, these move from being only between the staff and PLWD and include their relatives as well as planned interventions to get to know the person. Emotions discusses the emotional motivators for PCC, as well as the emotional impacts at stake for PLWD, their relatives and staff, that result from the way care is delivered. Finally, individual values are discussed and the effect these have on care delivery.

3.3.3.2.1 Connections

This section focuses on the interactions between staff and PLWD which facilitate or cause barriers to PCC. Interactions are powerful and could preserve the personhood of a PLWD. Through interactions a trusting nurse-patient relationship

could be established, which was key for delivering PCC and involved verbally engaging with the persons emotions, alongside activities as well as non-verbal communication (Brossard Saxell *et al.*, 2019, p. 16) (Finding 5d).

When interactions and communication are not adapted to suit the needs of PLWD they can experience negative emotions such as feeling rushed, excluded from decisions and fearful about discharge (Reilly and Houghton, 2019). Although the importance of relationships was recognised and felt to be a prerequisite to good care, there were barriers to staff being able to form relationships, particularly when they felt uncertain about psychosocial care, which could lead to a focus on physical care, or perceived a lack of time (Reilly and Houghton, 2019, Finding 5e).

When staff could adapt to incorporate connections with PLWD and promote their involvement in care through choices, relationships and social inclusion, it improved the experience of PLWD (Reilly and Houghton, 2019) (Finding 3f.) PLWD's experience could be distressing and negative if positive interactions were not facilitated (Reilly and Houghton, 2019) (Finding 3f.)

This section demonstrates how connections between staff and PLWD can impact the care experience and care delivery. Staff need to have the skills, ability, and willingness to adapt to facilitate interactions that enhance care, otherwise interactions could have a negative effect. In this section immediate interactions were discussed, however, interactions between other people such as relatives are also important to improve relationships and care delivery and these may involve planning to implement, rather than in-the-moment interactions. These are discussed in the next section.

3.3.3.2.2 Getting to know the whole person

This section identifies that getting to know the whole person involves more than focussing on interactions in the moment. There was a perspective that getting to know the person holistically was not something that happened in a static moment, it could be progressed through a series of actions, co-ordination, and a process involving relatives and colleagues (Brossard Saxell *et al.*, 2019, p. 15) (Finding 6b).

Relatives had an important role: their involvement aided the development of a holistic picture of the person, but they were also important for the social wellbeing of the PLWD in hospital and enabling the PLWD's views were heard (Reilly and Houghton, 2019) (Finding 6a).

Despite the benefits of involving relatives in the care of PLWD, there were strategic challenges to achieving this, as the processes to involve them were unclear and there was potential for disagreements if they made decisions which were not perceived to be in the best interest of the PLWD (Houghton *et al.*, 2016, p. 113)

This section demonstrates that getting to know a person involves more than momentary interactions; planning, co-ordination and communicating with people close to the person can promote a holistic view. The potential for disagreements that comes with involvement of more people demonstrates the emotional aspect of providing care within an acute hospital. The emotions relayed to providing PCC are discussed next.

3.3.3.2.3 Emotions

This section demonstrates that the hospital setting was imbued with emotions of the staff, PLWD and relatives, and these varied within different situations. The emotions

of staff were linked to job satisfaction (Gwernan-Jones *et al.*, 2020) and could affect their care approach, which influenced the experience of PLWD. PLWD and their relatives were all noted to experience significant emotions in response to the care provided within the hospitals.

Providing care within the inherent structures of the hospital caused emotional tension for healthcare staff, particularly nurses and HCAs. This could be exacerbated by staff: patient ratios, the complexity of caring for PLWD and the “conflict between opposing discourses, one around the nature of medical care, and the other around the nature of PCC” (Gwernan-Jones *et al.*, 2020, p. 11) (Finding 7b). The feelings of stress and frustration could be a direct result of having difficulty coping with the distress shown by PLWD and could be exacerbated by working practices. This included staff trying to cope with an PLWD who may be agitated, aggressive and resistant whilst feeling concerned about time pressures and staff shortages, leading to stress, guilt and exhaustion (Dewing and Dijk, 2016, p. 9) (Finding 7k).

Gwernan-Jones *et al.* (2020 p. 11-12) reported that when staff felt emotionally burdened, they could respond by creating a barrier between themselves and the PLWD, through physically disengaging, ignoring the PLWD or focussing solely on tasks and routines. This could be a way to preserve their own wellbeing.

The emotions of PLWD were also influenced by the experience of being in hospital. This was due to the disruption to their daily life and the physical and psychosocial environment, which PLWD perceived as a threat to their personhood, these feelings could escalate the signs of distress the PLWD displayed (Reilly and Houghton, 2019) (Finding 7e).

From the reviews it was clear that admission could be a challenging time for PLWD, who responded to the difficulties in a variety of expressed ways. The way staff engaged with these expressions was variable and there was the opportunity for staff to relieve some of the distress or add to it. Relatives also reported emotional reactions to the hospital admission, which was linked with their perceptions of the care that was being carried out. Relatives did not find their family members admission provided respite but were emotionally exhausted, their expectations did not fit with the task-focussed atmosphere (Dewing and Dijk, 2016, p. 8) (Finding 7j). Relatives were further frustrated by a lack of basic amenities such as chairs or refreshments and blamed staff for their perception of an inflexible hospital system (Dewing and Dijk, 2016, p. 8) (Finding 7j).

From this analysis it emerged that the emotions of staff, PLWD and their relatives are all influenced by the hospital environment. Congruent with the previous sections, they could be influenced by individual aspects as well as organisational aspects. Emotions were felt by all those involved in care and for staff were linked to their values. The next section will explore values and how these impact care.

3.3.3.2.4 Values

The reviews demonstrated the relationship between organisational structures and the behaviour of staff. The reviews also suggest that the actions and attitudes of staff could be influenced by their values and beliefs (Dewing and Dijk, 2016, p. 7). According to staff, good care involved providing for the physical and emotional needs of PLWD (Gwernan-Jones *et al.*, 2020, p. 6). Nurses felt their professional identity placed them in a position to ensure patients received PCC, in line with their belief and values. Some nurses' motivations came from their personal beliefs,

seeing PCC as fundamental to their role and required to see the person behind the diagnosis, assisting their rapport-building (Brossard Saxell *et al.*, 2019, pp. 12–13) (Finding 8b).

Whilst values and beliefs may influence care positively, attitudes towards PLWD were variable amongst staff and therefore addressing staff attitudes may be necessary to implement change (Dewing and Dijk, 2016).

3.3.4 Discussion of umbrella review

This umbrella review brought together findings from six reviews to explore the experience of PCC within acute hospitals from the perspective of PLWD, their relatives and staff. Alongside this, the barriers and facilitators to PCC were presented. **Error! Reference source not found.** Figure 3.3 has been created to display the overall themes which demonstrated that a series of organisational factors and individual factors contributed to the outcome of care. The outcomes were that care was person-centred or task-focussed; within these outcomes there were impacts on the emotions for all those involved. Currently, person-centred dementia care within hospitals remains in flux. Overall, PCC had benefits for PLWD, staff and relatives. There were entwining individual factors and organisational factors which could contribute to PCC. The literature suggests that, currently, for PCC to be achieved the individuals involved in care are required to make the adaptations, as opposed to the organisational factors being adapted. This does represent the dichotomy at play and the conflicts in care happening within the acute hospital setting (Gwernan-Jones *et al.*, 2020).

Analysis of the reviews demonstrates that within the literature about PCC within acute hospitals there are often discussions about physical care, which may be

represented in a range of ways. Physical care, which can be assumed to include hydration care, may be described as a factor in task-orientated care, which is prioritised but can be damaging to PCC (Gwernan-Jones *et al.*, 2020) or an area that is potentially forfeited because of a focus on safety (Houghton *et al.*, 2016), or an aspect of care complimented by interactions and a holistic approach making physical care person-centred (Brossard Saxell *et al.*, 2019). Within the literature reviewed in this umbrella review, physical care is represented as a broad, all-encompassing category of care, however, in a hospital setting there are a range of physical healthcare needs and actions to which the authors could be referring. The detail of individual aspects of physical care and how they are facilitated in a person-centred way is underdeveloped. Research which specifically explores individual aspects of physical care will contribute to the understanding of PCC within acute hospitals.

Additionally, the umbrella review indicates that whilst interactions and individual factors are important in PCC, research which only focusses care at the individual level and solely on interactions may not fully identify broader organisational barriers and facilitators to PCC. PCC is not consistently being carried out within hospitals, hence the overall finding that PCC within hospitals is in flux.

3.3.5 Conclusion of umbrella review

The umbrella review benefits the understanding of PCC within acute hospitals by combining evidence from six reviews. One limitation of this review is that, due to the nature of a PhD, the data extraction and summary was conducted by one reviewer, which is not in keeping with the recommendations followed (The Joanna Briggs Institute, 2014). However, by demonstrating how data analysis was completed (see

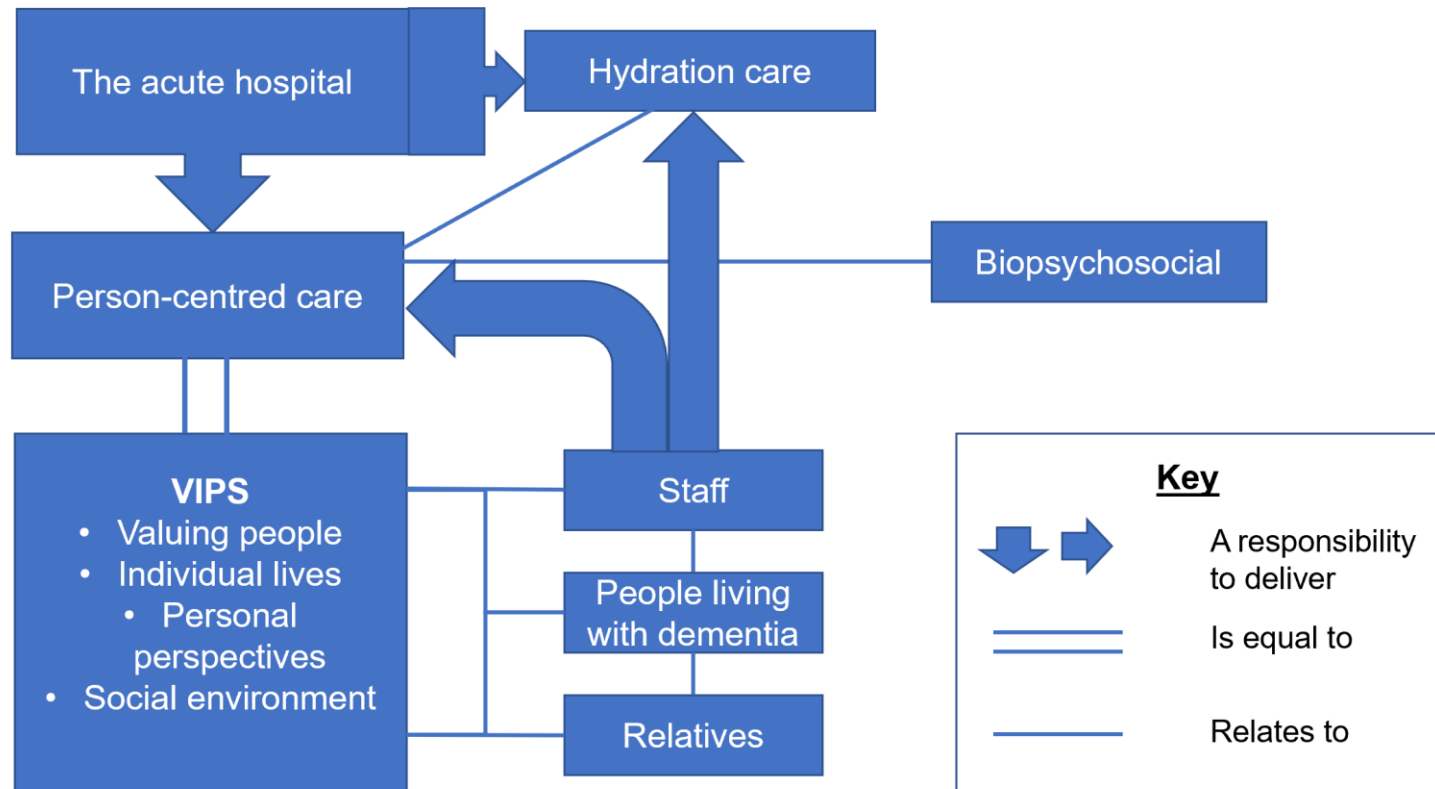
appendix six and seven), this adds to the transparency and rigour. The umbrella review demonstrates that PCC within hospitals is a topic of importance for research. The barriers and facilitators are complex and there are still aspects which require further investigation.

3.4 A concept map aligning person-centred care and hydration in acute hospitals

This chapter has explored the concept of PCC and provided a justification for defining PCC using VIPS (Brooker and Latham, 2016). The chapter has also examined the concept of PCC within acute hospitals. It can be concluded that PCC is in keeping with a biopsychosocial approach to care and cannot be achieved without consideration for the physical health needs of a PLWD. Within acute hospitals, hydration care is a physical aspect of care which could be carried out in a way which is task-focussed or person-centred. As several concepts have been introduced within the previous chapters there is benefit to presenting the concepts and their relationships. When considering multiple concepts for use within a study, concept mapping can be a useful tool for displaying the concepts and the relationships among them (Maxwell, 2005a). A concept map illustrates concepts which allude to assumptions of reality, what can be known and how these can be known; these concepts relate to the ontological and epistemological views within research (Welford *et al.*, 2012), which will be discussed in chapter four (section 4.2.1). Figure 3.4 shows a concept map of the concepts of the acute hospital, person-centred care, VIPS, and hydration care and how these relate, based on the literature reviews conducted. Figure 3.4 illustrates the connections between the responsibility the acute hospital and staff have to provide PCC for OPLWD, showing

that PCC is synonymous with VIPS. Additionally illustrated, is that the hospital and staff have a responsibility to provide hydration care and PCC, which involves the PLWD, the staff and relatives and therefore all should be included in hydration care within the hospital. Additionally, PCC is shown as being related to biopsychosocial care.

Figure 3.4 Concept map of the acute hospital, person-centred care, VIPS Framework and hydration care



The research aim will now be revisited, with the research objectives and the research questions presented.

3.4.1 Research aim, objectives and questions

Aim

The research aim, introduced in section 2.10 is revisited here. This research aims to use the concept of PCC to explore and describe the factors influencing hydration care and the associated experiences of OPLWD in acute hospital wards. In addition, study objectives are presented which incorporate the need to explore the topic, taking into consideration the staff, the OPLWD and their relatives, in line with person-centred care.

Objectives

The study objectives are to:

- Explore any ways the context of the acute hospital or the ward environment impact on hydration care of OPLWD.
- Observe the interactions and approach of staff during hydration care for OPLWD in acute hospital wards.
- Explore hospital staff perceptions about hydration care for OPLWD and their associated roles.
- Explore the views and preferences of OPLWD for hydration at home and how these compare with hydration in hospital wards.
- Explore the views of the relatives about hydration care within the hospital and gain information about the OPLWD's usual routine and abilities at home related to hydration care.
- Identify practices that promote person-centred hydration care in an effective way for OPLWD in acute hospital wards.
- Identify any barriers to person-centred hydration care for OPLWD in acute hospital wards.

Research questions

1. How does the acute hospital affect person-centred hydration for older people living with dementia (OPLWD)?
2. How do ward environments affect person-centred hydration care for OPLWD?
3. How do staff view their roles related to hydration care and how does this compare with observations of hydration care?
4. Using the concept of PCC how can hydration care for OPLWD in acute hospital wards be facilitated and what are the barriers?

3.5 Chapter summary

This chapter introduced the concept of PCC and presented the development of the concept within the field of dementia care through the work of Tom Kitwood (1997). Multiple definitions of PCC were presented and the use of the VIPS Framework was justified (Brooker and Latham, 2016). Literature related to PCC within acute hospitals was explored through an umbrella review. The chapter demonstrates that PCC is an important concept for dementia care which has complexities to being achieved within acute hospital settings. There is a need for research which progresses the understanding of PCC within acute hospitals, particularly looking at the individual physical aspects of care which may or may not be completed with adherence to PCC. The work on PCC demonstrates that to understand and provide PCC within an acute hospital involves inclusion of the staff, the OPLWD and their relatives, which will influence the research methodology. The methodology is explained in chapter four.

4 Methodology

4.1 Introduction

This chapter revisits the research questions which were introduced at the end of chapter two. The methodological choices made to answer the research questions are introduced, explained, and justified. The practical research issues such as patient and public involvement, ethical considerations and gaining access to the setting are then discussed. Following this, how the data were collected is explained and the participants are introduced. The use of multiple data collection methods, including interviews, documentation analysis and direct observation, are then discussed. The chapter concludes by demonstrating how framework (Ritchie and Spencer, 1994) was used to analyse the data and how the integration of the data from the multiple data collection methods was conducted.

4.2 Methodological considerations

This section explores the foundations of the methodological decisions. Researchers' methodological decisions have been likened to a "scaffold" holding the research in shape that provides structure (Thomas, 2013, p.126). This scaffold connects the research purpose, questions and the way data are collected. This research aims to investigate the phenomenon of hydration care within acute hospitals, using the concept of person-centred care (PCC). Presented in the concept map section to answer the research questions developed from the previous chapters and revisited here.

Research questions

1. How does the acute hospital affect person-centred hydration for older people living with dementia (OPLWD)?
2. How do ward environments affect person-centred hydration care for OPLWD?
3. How do staff view their roles related to hydration care and how does this compare with observations of hydration care?
4. Using the concept of PCC how can hydration care for OPLWD in acute hospital wards be facilitated and what are the barriers?

To answer these questions, it is necessary to investigate certain areas: an acute hospital, acute hospital wards, staff roles and views. As the questions incorporate an explicit concept, person-centred care (PCC), this study does not just require staff delivering care to be participants in the research but also the OPLWD and their relatives. Encompassing multiple people's perspectives, within a social setting into research involves querying philosophical assumptions, further discussed in section 4.2.1.

4.2.1 Epistemology, ontology and paradigm discussion

This research aims to explore and understand contextual elements as well as the individual perspectives and actions of staff, OPLWD and their relatives when facilitating hydration care. Hydration care occurs within a ward environment, so answering the research questions required exploration of hydration care within acute hospital wards, as well as exploring the acute hospital context. To investigate a social setting and multiple perspectives requires addressing questions about what paradigm this research is situated within. A research paradigm is "a set of very

general philosophical assumptions about the nature of the world (ontology) and how we can understand it (epistemology)” (Maxwell, 2005a, p. 36). Paradigm positions exist on a spectrum; at one end are positivists, who favour quantitative methods, at the other end are constructivists, who favour qualitative methods. Often, philosophical debates about opposing paradigms are termed quantitative-qualitative ‘paradigm wars’ (Punch, 2005, p. 27). However, as the positions are situated on a continuum, research practice can lie somewhere in-between the two extreme ends (Creswell, 2003). Related to this exists another continuum addressing whether, and to what extent quantitative or qualitative methods can be mixed within research, with purists at one end, who do not view mixing possible and pragmatists at the other, who advocate mixing methods (Rossman and Wilson, 1985).

Some argue paradigm divisions are divisive and therefore counterproductive to social research (Onwuegbuzie and Leech, 2005). However, the paradigm research is situated in has importance, as it lays the foundations for the study. Arguably, there are limitations to the choice a researcher can make, as worldviews exist somewhat before a research methodology is developed.

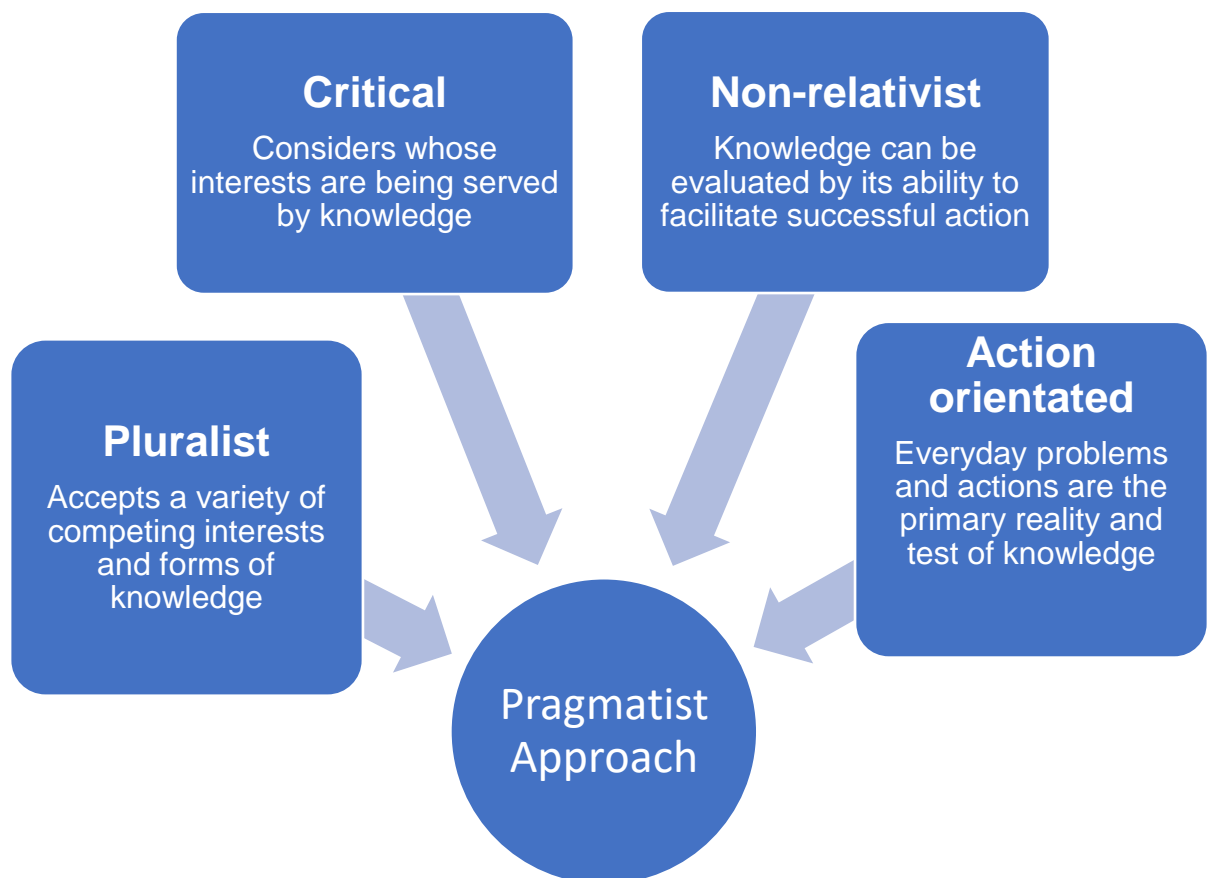
For me, as the research topic was a real-world issue, situated in a clinical environment, the aim of the research was gaining an understanding of the phenomenon which would be useful for clinical practice. This view still required that I address assumptions of epistemology and ontology. Whilst I viewed the hospital as having an observable, physical social reality, I had limited ability to influence the parameters of the reality; it was not an object that could be manipulated. Manipulation would not fit with the research aim to understand the phenomenon in its natural setting either. I also recognised that the care provided on the wards

involved multiple people, therefore, although I considered there was a physical, albeit, social reality within the hospital, the reality was also influenced by and experienced differently for each person. I could not situate myself as a purist in the discussion of paradigms and found myself considering the paradigms which acknowledged there may be multiple approaches useful to study real-world problems. Additionally, within considerations for this research there were drivers which held importance beyond the constructivist or positivist paradigm, including ethical and practical considerations. These included the needs of participants who have a cognitive impairment: an OPLWD admitted to an acute hospital is likely to be experiencing an additional illness, and healthcare staff participants are busy working in this environment. My understanding of these factors had developed through prior experience of working clinically as a mental health nurse and of conducting research within acute hospital environments (Sampson *et al.*, 2019), as well as approaches used by other researchers in this field. I felt to answer the research questions sufficiently, practically and ethically required the use of a variety of methods; this approach can be defined as pragmatic.

With a pragmatic approach the researcher begins with questions that need to be answered and then the methods are chosen; the questions may come from a range of sources including practical and professional issues, which suits healthcare research (Punch, 2014). This approach is often associated with mixed methods research (Creswell, 2015). Pragmatists are less concerned with philosophical rules and purity and more interested in the best methods to answer the research question, acknowledging this often requires use of both quantitative and qualitative methods, although this is not essential. Describing how a pragmatist approach can be beneficial for healthcare research, Cornish and Gillespie (2009) define the four

philosophical underpinnings of this approach, illustrating that it can assist with the complexities of real-world problems as it accounts for conflicting forms of knowledge. Figure 4.1 illustrates the philosophical underpinnings.

Figure 4.1: Pragmatist approach and defining features



Developed from Cornish and Gillespie (2009, p. 803)

As demonstrated in the literature review (chapter two), the process of hydration care for OPLWD has not been explored in detail within the setting of an acute hospital or

using a theory of PCC. When a phenomenon, which cannot easily be measured, requires exploration, qualitative research is appropriate, especially if a complex, detailed understanding can be facilitated by talking to people or visiting their workplace (Creswell, 2013, pp. 47–48). As the main purpose of this research is to explore the complex phenomenon in-depth, the study is weighted towards qualitative research.

As discussed, the paradigm frames research decisions, however, it does not address the process for carrying out the research. There are other research decisions which contribute to this, particularly choosing a specific research design. The methodological design decisions are discussed next.

4.3 The benefits of a case study over other research methodologies

Several methodologies were considered during the design stage, however, case study was considered the most appropriate methodological choice based on the research aims and questions, the patient population being studied and the hospital environment, which is justified in this section. Due to the patient group under investigation, OPLWD, who were in hospital and therefore likely to be unwell, it was considered that there could be some challenges to verbal communication. Therefore, some approaches which heavily rely on interviews and narrative accounts were ruled out immediately, such as phenomenology or grounded theory. Additionally, it was felt that interviews alone would not be sufficient to answer the research questions. Due to the importance of gaining information from multiple participants, such as staff, patients and relatives, and observing hydration care taking place within the ward environments, a design approach which could

incorporate these elements was essential. Ethnography was considered, however, as the focus of ethnography is on the culture of the group (Creswell, 2013) this was not felt to align as directly with the objectives of the research as case study methodology, which is described in section 4.3.1. Additionally, it was felt that being able to understand care on multiple wards, allowing in-depth assessment across and within the ward environment would better suit the research aims, objectives and questions, which would not be as achievable with ethnography compared to case study. Case study is discussed further in the next section.

4.3.1 Case study

Case study is a methodology which provides in-depth exploration of a contemporary bounded system or systems, without controlling variables, to gain an in-depth understanding, from multiple perspectives, using multiple methods and sources of data to examine relationships and processes (Creswell, 2013; Thomas, 2016). Therefore, case study methodology aligned well with the aims of the research to explore hydration care within and across acute hospital wards, in-depth and from the perspective of staff, OPLWD and their relatives.

There are two authors commonly credited with progressing case study techniques: Yin (2014) and Stake (1995). Their different approaches to case study are partly rooted in their relationship to the research paradigm. Stake (1995) explicitly uses a qualitative approach to case study and states this sits within a 'subjective research paradigm' (Stake, 1995, p. 45). Placing Yin's approach to case study in one paradigmatic approach is more complicated. Yin (2014, p. 17) argues case study is "all-encompassing" and is flexible with different research paradigms, although he acknowledges that his methodology appears to be orientated to a realist paradigm.

The flexibility of case study is echoed in the views of nurse researchers who argue case study can act as a bridge across research paradigms and is a process for using the methods which best investigate the research topic (Luck *et al.*, 2006), thus it can be philosophically pragmatic (Brogan *et al.*, 2019; Creswell, 2013, p. 29).

The research design of this study was predominantly guided by Yin's (2014) work, as this was felt to be the best fit with a pragmatic approach. Additionally, Stake (1995) advocates the use of a single case, and due to the research questions, it was felt comparison across multiple wards, as cases, would provide a better understanding of the topic. Selecting the case is discussed in more detail through this section.

Yin (2014, p. 2). states case study is used to: "investigate a contemporary phenomenon (the 'case') in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident." He also explains that case study is an appropriate method in situations when asking "how" or "why" research questions, which was applicable to the research questions for my study. He describes five key aspects to case study research design:

1. A case study's questions,
2. Propositions,
3. Units of analysis (or "case"),
4. The logic linking the data to the propositions,
5. Criteria for interpreting the findings.

The use of study propositions further distinguishes case study from other qualitative methodologies such as ethnography or grounded theory because study propositions rely on the role of theory development prior to the collection of data. Yin's view is

that study propositions are developed through literature reviews, discussions with colleagues or self-reflection; they do not need to resemble grand theories in social science. Based on literature reviews and professional experience, the study propositions developed are outlined in table 4.1; the propositions are linked to the research questions and the data collection methods used. Study propositions enable the researcher to seek out relevant evidence. Yin (2014) identifies six possible sources of evidence: documentation, archival records, interviews, direct observation, participant-observation and physical artifacts. This study uses three of these sources: documentation, interviews and direct observation, further discussed in section 4.7.

Table 4.1 Study propositions and research questions linked to data collection methods

| Propositions | Research Questions | Interviews | Observation | Documents |
|---|---|--|--|---|
| OPLWD who are admitted to acute hospitals are likely to require assistance with oral fluid intake. | <p>How does the acute hospital affect person-centred hydration for older people living with dementia (OPLWD)?</p> <p>How do ward environments affect person-centred hydration care for OPLWD?</p> | <p>Patient interviews about hydration care needs and opinions. Interviews with staff about their roles. Interviews with relatives about the OPLWD's needs.</p> | <p>Observation of the care of OPLWD, including all staff and patient interactions, gathering field notes.</p> | <p>Fluid care needs documented in healthcare notes, fluid intake chart, preferences documented in care records.</p> |
| PCC is best practice for OPLWD but may not be implemented well in acute hospital ward environments, where task-focussed approaches dominate. Hydration may be carried out in a task-focussed way. | <p>How do ward environments affect person-centred hydration care for OPLWD?</p> <p>How do staff view their roles related to hydration care and how does this compare with observations of hydration care?</p> | <p>Interviews with senior staff, to include views about: staff training, priorities of care for OPLWD, how quality is measured.</p> | <p>Observation of the care of OPLWD, including all staff and patient interactions, gathering field notes; observation of interactions using QUIS tool.</p> | <p>Hospital policies; patient care records, OPLWD's documented preferences.</p> |
| Assisting OPLWD with oral fluid intake is an opportunity for PCC, which may improve patient care. | <p>Using the concept of PCC how can hydration care for OPLWD in acute hospital wards be facilitated and what are the barriers?</p> | <p>Interviews with staff on wards; interviews with relatives; interviews with patients.</p> | <p>Observation of patient and all staff and patient interactions gathering field notes; QUIS tool.</p> | <p>Fluid care needs documented in healthcare notes; OPLWD preferences documented and recorded.</p> |

Defining the 'case' is fundamental in case study and is defined based on its ability to answer the research questions. The case may be concrete, such as individuals, small groups or organisations, or less concrete, such as communities, relationships or projects. To answer the research questions, revisited in section 4.2, there are three cases: three wards in an acute hospital. Although a case study can be conducted with a single case, Yin (2014) emphasises the benefits of multiple case studies, particularly for strengthening analytical conclusions. Having three cases provided an opportunity to compare across the three cases as well as describe the phenomenon within each case. The cases were chosen as they all provide a different focus of care within the hospital (acute, elderly medicine, surgery) which all have high numbers of OPLWD admitted. The setting is further described in section 4.5.4.

Yin (2014 p. 33) also describes "bounding the case" which involves deciding which aspects of a group are included in the case. The boundaries of this research were defined and aided by using "embedded units of analysis." The embedded units of analysis were the OPLWD who were being studied and the staff who interacted with them. This was in keeping with using the concept of person-centred care, as I was able to explore how care was provided to individual OPLWD. Table 4.2 displays how utilising aspects of the VIPS Framework (Brooker and Latham, 2016) assisted with ensuring areas of data were captured which would provide an understanding of hydration care as it related to person-centred care. Interviews with a ward leader, or a hospital-wide leader were also part of the data collection, even if they had not interacted with an OPLWD recruited to the research, to enhance the contextual findings. Contextual findings also relate to the criteria required to explore PCC.

Table 4.2: Linking person-centred care (VIPS Framework) to the data collection methods

| VIPS Framework Category | VIPS Framework sub-category | Hospital-wide leadership interviews | Policy documentary analysis | Ward leader interviews | Direct Observation | Clinical documentary analysis | Patient interviews | Ward staff interviews | Carer interviews |
|------------------------------|--|-------------------------------------|-----------------------------|------------------------|--------------------|-------------------------------|--------------------|-----------------------|------------------|
| Valuing people | Training and staff development | ✓ | ✓ | ✓ | | | | ✓ | |
| | Management ethos and vision | ✓ | ✓ | ✓ | ✓ | | | ✓ | |
| | Quality Assurances | ✓ | ✓ | ✓ | ✓ | | | | ✓ |
| | Service environments | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ | ✓ |
| | Human resources | ✓ | | ✓ | | | | ✓ | |
| Individual lives | Care and support plans | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Regular reviews | | | | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Individual preferences | | | | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Activity and occupation | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Personal possessions and life story | | | | ✓ | | ✓ | ✓ | ✓ |
| Personal perspectives | Communication is key | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Physical environments | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Physical health | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Advocacy | | | | ✓ | ✓ | | ✓ | |
| | Empathy and Acceptable risk | | | ✓ | ✓ | | | ✓ | |
| | Challenging behaviour as communication | | | | ✓ | ✓ | | ✓ | |
| Social environment | Enabling | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Relationships | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Respect, warmth and validation | | | | ✓ | | ✓ | ✓ | |
| | Inclusion and part of the community | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ | ✓ |

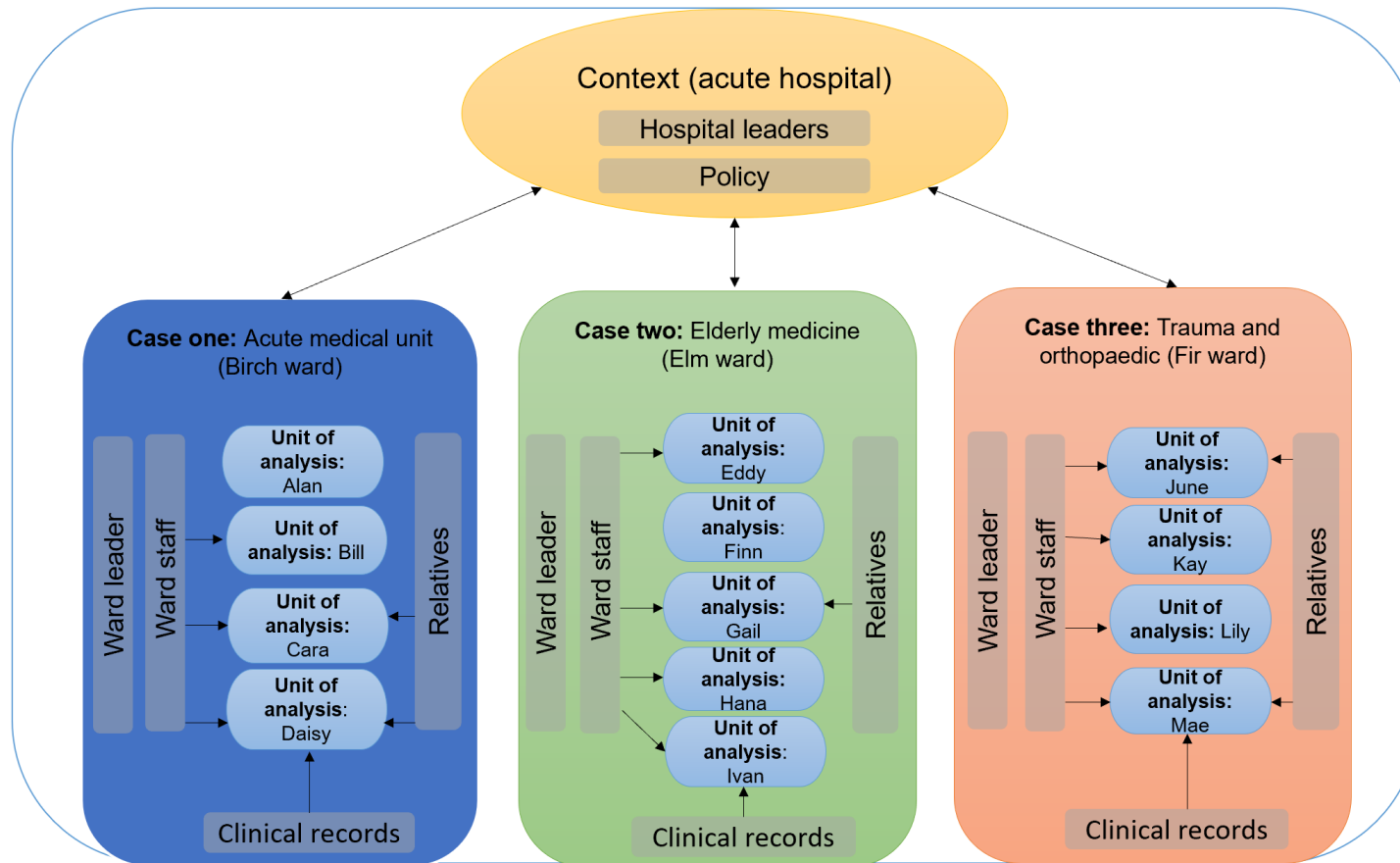
(adapted from Brooker and Latham, 2016)

Table 4.2 demonstrates how the aspects of VIPS framework (Brooker and Latham, 2016) were considered to be represented by various data collection methods would provide the required insights into acute hospital care and enable the research aims to be achieved. As well as providing a way to decide data collection methods the VIPS framework was used to develop the interview topic guides for each area, which are discussed further in section 4.7.1.1.

As described the case study design was a multiple-case study with embedded units of analysis, which were the OPLWD admitted to the wards. Figure 4.2, using pseudonyms, presents how Yin's framework was applied in the case study design, with the context (acute hospital), cases (wards) and units of analysis (patients) and the staff that interacted with them, as well as their relatives. The context was explored through hospital leader interviews and hospital policy, discussed further in section 4.7.1.2 and 4.7.2.1. The three cases include the ward leader, who were interviewed about the ward, discussed in section 4.7.1.3.1. The cases also include the units of analysis (the OPLWD) whose care was observed, which is discussed in section 4.7.3. The arrows linking the ward staff and relatives to OPLWD indicate the interviews that were carried out with staff and relatives which were connected to the OPLWD, discussed in sections 4.7.1.3.2 and 4.7.1.3.4. The clinical documentation is also connected to the OPLWD by an arrow, as these were also connected to the OPLWD, clinical documentation analysis is discussed further in section 4.7.2.2.

Figure 4.2: Multiple case study design with units of analysis*

*NB: all names used are pseudonyms



A further illustration of the participants recruited for each aspect of the case study can be found in section 4.6, figure 4.3. The fifth aspect of Yin's case study framework - criteria for interpreting the case study findings - will be discussed in section 4.9 where I describe the analytical decisions.

As described in sections 4.2-4.3 and demonstrated in tables 4.1 and 4.2, using multiple data collection methods was fundamental to answering the research questions. Case study is a methodology which aligned the research objectives, questions and use of the developed concepts that required multiple data collection methods to be used.

4.4 Validity

Yin (2014) uses the terms validity and reliability to identify factors that determine the quality of research; these terms are regularly used in quantitative research (Noble and Smith, 2015), although validity is used in qualitative research also (Maxwell, 2005b). Maxwell explains that all research should aim to produce valid research, although the idea that research methods themselves produce validity is associated with a positivist view of research (Maxwell, 2005b). Therefore, the methods themselves are not the way of achieving validity, but there are several aspects which can improve validity. In qualitative research, the terminology of rigour is used for processes associated with validity, and often includes four concepts: credibility, transferability, dependability and confirmability (Lincoln and Guba, 1986). Additionally, concepts such as reflexivity and triangulation are also useful when evaluating rigour in qualitative research (Moorley and Cathala, 2019). These terms are further explained in table 4.3. Triangulation can have differing meanings in

research, so defining how the term is being used is important (Bergen and While, 2000). Yin's use of triangulation relates to the benefits of using multiple sources of data to study one phenomenon (Yin, 2014, pp. 119–122), which is applicable to this study. Yin specifies that the multiple sources of data should all address the findings; termed convergence of evidence, which leads to construct validity of the case study. Triangulation is further explored in section 4.9.3 when integration of the multiple methods is discussed. Table 4.3 summarises how rigour was addressed in this study.

Table 4.3: Approach to rigour

Adapted from Lincoln and Guba (1986)

| Approach to rigour | Techniques that apply to the approach | Application to this research |
|---|---|---|
| Credibility | Prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, member checks | <ul style="list-style-type: none"> • 132 hours of observation • Data triangulation (observation, interviews and documentation analysis) • Quantitative data to enhance qualitative findings • Identification of 'outlying' pieces of data • Regular discussion with supervisors about process, progress and findings |
| Transferability | Thick descriptive data | <ul style="list-style-type: none"> • Description of setting |
| Dependability and confirmability | External audit, audit trail and an external auditor | <ul style="list-style-type: none"> • Process of research documented in thesis • Transparent analysis strategy • Use of participants' own words when presenting findings to provide rich descriptions |
| Reflexivity | Critical self-reflection | <ul style="list-style-type: none"> • Research diary kept- including reflections prior to data collection as well as during data collection and analysis |

Although the approaches taken for rigour are presented at this point of the thesis, they were not a static moment, they required consideration at design stage and throughout the research process until the conclusions were made and documented.

I will now discuss the steps taken to carry out the research.

4.5 Setting up the research

4.5.1 Patient and public involvement

Patient and public involvement (PPI) in research is increasingly a prerequisite for being awarded research grants due to the recognition that it is a cornerstone of quality research with a multitude of benefits (Moore and Reynolds, 2018), including increased quality, relevance and impact of health research (Brett *et al.*, 2014; Miah *et al.*, 2019). Public involvement in research has been defined as: “Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (INVOLVE, 2012). Due to the time and financial limitations constraining a PhD research project, I was unable to encompass all possible elements of PPI, but I did seek feedback on the topic and research materials as, discussed in this section. Additionally, an established report was used to determine that the research topic was a priority for the patient population, as discussed in section 1.4 (Alzheimer’s Society, 2013). This report found that two priorities for research were:

- *“5: What is the best way to care for people with dementia in a hospital setting when they have acute health care needs”*
- *“6: What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake”* (Alzheimer’s Society, 2013, p. 3)

On 26th June 2017, direct PPI was also sought through application to the Alzheimer’s Society Research Network volunteers for comment on the study design, patient participation information and topic guides. The application was accepted and provided written confirmation that the network agreed that this was an important topic to research. On 16th August 2017 I received feedback from a network volunteer with positive comments on the information sheets and topic guides, with one suggested amendment to the patient interview guide which I incorporated. PPI is

deemed to have positive implications ethically, in establishing an improved consent process and an assurance the research is ethically acceptable (Staley, 2009). Further ethical considerations, including the formal ethical processes are discussed next.

4.5.2 Ethical considerations

Ethical considerations run alongside all research undertaken and must consider the principles of ethics, codes of conduct and research guidelines (Holloway and Galvin, 2017). In a seminal work, Beauchamp and Childress (2008) outline four principles for ethics in medical research:

- 1) Respect for autonomy,
- 2) The principle of nonmaleficence,
- 3) The principle of beneficence,
- 4) The principle of justice.

Ethical approval was gained by an NHS Health Research Authority Research Ethics Committee (HRA REC), see appendix eight and the London South Bank University School of Health and Social Care ethics panel. Consent, linked to respect for autonomy, is a major aspect of ensuring research follows ethical principles. In research involving OPLWD particular care must be taken that any OPLWD providing consent has the capacity to provide informed consent, without ruling out the option for OPLWD to participate in research, which would be ethically unjust (Hampson and Morris, 2018). To ensure ethical participation and consent procedures I had options for recruiting OPLWD participants who had capacity to consent and those who lacked capacity to consent, and took the approach that consent is an ongoing process.

To recruit participants who lack capacity involves adherence to Section 32 of the Mental Capacity Act (2005). This requires seeking and appointing a consultee. Importantly, a consultee does not consent on behalf of a person who lacks capacity; their role is to advise on whether the person should take part and particularly to provide advice about what the person's opinion may have been if they had capacity to consent. The consultee then signs the declaration form based on the above information if they feel the person would not have objected and they are willing to act as a consultee. There were discussions during the HRA REC to ensure my understanding of Section 32 and that the consultee information was accurate.

I ensured my skills were up-to-date by undertaking training provided by the National Institute of Health Research, 'Consent with adults lacking capacity,' to complement my established clinical skills using the Mental Capacity Act (2005) to assess capacity. Table 4.4 shows the consent approach for each participant.

Table 4.4 Participant and consent approach

| Participant | Consent approach |
|---|---|
| <p>Older person living with dementia: with capacity to consent (observation only or observation and interview)</p> | <p>Prior to any recruitment, I asked the staff working with the OPLWD if they felt the participant had capacity to consent to research.</p> <p>If they felt they would have capacity I asked them to ask the OPLWD if they consented to speak to a researcher.</p> <p>If the OPLWD agreed to speak with me I met with them and explained the research, providing the participant information leaflet (see appendix nine) and, if required, read it aloud to them. I then agreed a mutually convenient period between one and 24 hours to return and check if they consented to take part in the research.</p> <p>On my return, in line with the Mental Capacity Act (2005) I checked the person's retention, understanding, view and ability to communicate their choice to me before a consent form was signed.</p> <p>If the person declined to take part, I thanked them for their time and my contact with them discontinued.</p> <p>If they agreed, the consent form was signed (see appendix 10), two copies were made and one given to the OPLWD and one copy added to their clinical records.</p> <p>At this point I reminded the OPLWD that they could withdraw their consent at any time.</p> <p>I then organised when I would commence the first observation, letting the OPLWD and the staff know.</p> <p>At the start of each observation, I checked that the OPLWD was still in agreement.</p> <p>I offered the option to take part in or decline an interview and reminded them taking part in an interview was not required just because they had consented to observation.</p> |

| Participant | Consent approach |
|--|---|
| <p>Older person living with dementia: lacking capacity to consent (observation only or observation and interview)</p> | <p>If staff indicated that they thought the person would lack capacity to consent in the research, the use of a personal consultee was sought.</p> <p>I asked staff to contact the OPLWD's identified next of kin (NOK) and ask whether they would be willing to speak with me about research.</p> <p>If they consented, I telephoned them and explained the research, if they were interested, I asked if there was a convenient time we could meet to discuss the study. I also asked if they would like me to send a copy of the 'consultee information leaflet' (see appendix 11) prior to the meeting and offered to send this by email or post.</p> <p>At this meeting I provided them with a further copy of the consultee information leaflet and answered any questions they had. I informed them a consultee does not 'consent' on the OPLWD's behalf, instead they provide information about what the OPLWD's previous wishes and views may have been on taking part in research. From this discussion I asked if they were willing to act as a consultee for the OPLWD and sign the consultee declaration form, they were given the choice not to answer the question or to decline to sign the consultee declaration form (see appendix 12).</p> <p>No one chose not to provide the information. One person did not sign the consultee declaration form.</p> <p>Once a person signed the consultee declaration form, two copies were made, one was kept in the patient clinical notes and the other was given for the consultee to keep.</p> <p>I then liaised with the ward to agree a suitable time to conduct the first observation. I also asked the consultee if they would be willing to take part in a 'relative interview' at this time if they were eligible.</p> |
| <p>Relatives (interview)</p> | <p>I asked ward staff to make first contact with eligible relatives face-to-face or by the telephone to ask if they agreed to speak to a researcher about research.</p> <p>If the relative declined my contact ended there.</p> <p>If they accepted, I telephoned them or spoke with them face-to-face about the research and provided them with a relative's participant information leaflet (see appendix 13) either electronically or by paper. I gave them time to read this and then gave them the opportunity to consent or decline taking part.</p> <p>If they consented to the research a time was made to meet in person to sign the consent form (see appendix 14) and a copy was provided to them to keep.</p> <p>If they declined my contact with them ended at this point, unless their relative was consented to take part in the observation and they were present during the observation period.</p> |

| Participant | Consent approach |
|---|---|
| <p>Ward and ward staff (observation)</p> | <p>To recruit wards and the ward staff into observation I completed a two-step approach.</p> <p>First, I met with the ward sister, explained the study, provided an information leaflet and letter (see appendices 15 and 16) and answered any questions related to the research.</p> <p>I then asked for the ward sister to consent the ward into the observation aspect of the research by signing a ward consent form (see appendix 17).</p> <p>I also requested and gained agreement that they would email all staff members the study information, my details and give staff the option to 'opt out' of the observational element of the research (no staff opted out at this stage). A copy of the email is available in appendix 18).</p> <p>I also gained permission to display research posters (see appendix 19) with study information, a photo of me, my contact details and a further opportunity for staff to contact me - no staff contacted me directly.</p> <p>The second aspect of consent was through verbal checking. At the start of all observation periods, I introduced myself to the staff in the bay, explained my role and purpose of my attendance and provided a further opportunity for opting out (no staff opted out at this stage).</p> <p>If appropriate, I also asked the ward leader at this stage if they consented to an interview and asked them to sign a consent form (see appendix 20).</p> |
| <p>Ward staff (interview)</p> | <p>Prior to, during or shortly following an observation period I approached staff working directly with the OPLWD to discuss the research and explain that I hoped to conduct short interviews with staff on the ward. If they were interested, I gave them a participant information leaflet (see appendix 21) and organised a time to speak with them once they had read it.</p> <p>I then met with them, answered any questions and asked if they consented to the interview.</p> <p>If they did consent, they signed the consent form (see appendix 22), and a copy was made and given to them to keep.</p> <p>If they declined, my contact with them ended, unless they were present during an observation.</p> |

To view a flowchart of the study entry and exit points, with consent and data collection please see appendix 23.

4.5.3 Gaining access: gatekeepers

In different stages of research, contact with gatekeepers are required. Gatekeepers are people who can grant or withhold access to the setting (Holloway and Wheeler, 2010, p. 47). For this research there were informal and formal stages of gatekeeping at two levels - hospital and ward. Formally, access to the hospital was sought via the hospital NHS Research and Development department alongside ethical approval from the NHS Research Ethics Committee. To gain support for the study within the hospital, my PhD director of studies, who had an established professional network within the hospital, sent an email of introduction to the ward gatekeepers. The email outlined my role and the objectives of the study. The initial email was sent to the chief nurse, who then sent emails to the deputy chief nurses, who then emailed the matrons. Once agreement had been ascertained at this level, I contacted the three ward sisters to organise meetings to discuss the research. During these meetings, details about the research were provided (see appendix 15) and practical research issues discussed and organised, for example, where were the most appropriate places to put up research posters (see appendix 19).

4.5.4 Setting

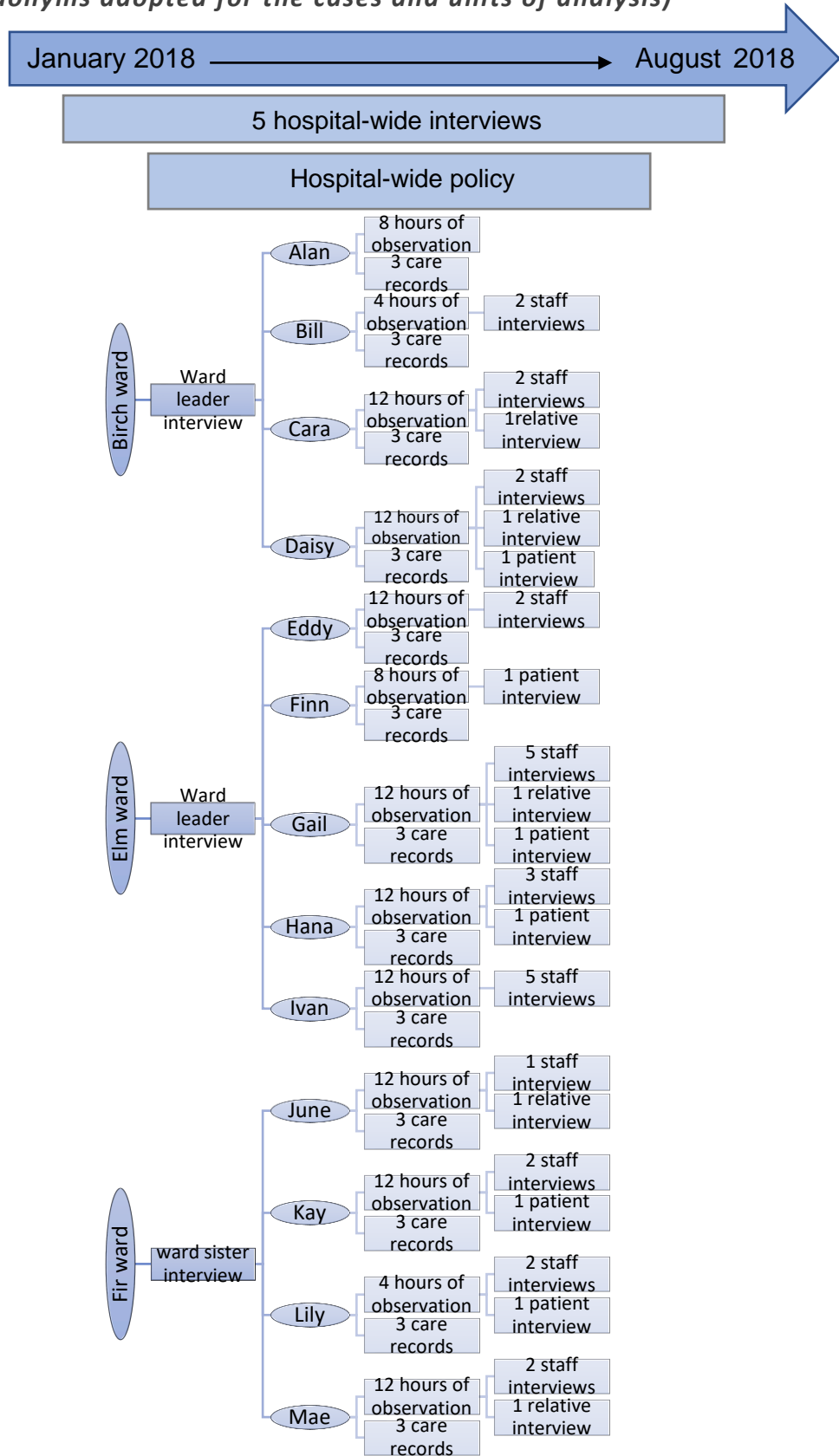
The research setting was one site of a multi-site acute, inner-city, teaching hospital. As one research question was to discover successful strategies to provide hydration care, the hospital was chosen as it had received an overall rating of 'good' from the regulator, the Care Quality Commission (CQC). Pseudonyms were given to three wards chosen. Birch is an acute medical ward, Elm is an elderly medicine ward and Fir is a trauma and orthopaedic ward. They were a variety of sizes and layouts, comprising single-sex, open bays with 4-6 beds and one or two individual side

rooms between the bays. The staffing is reported in the findings chapter (section 5.4.2). The wards were chosen as they were known to have high numbers of older patients admitted, resulting in many OPLWD being treated.

4.6 Carrying out the research

Although the research utilised multiple cases, the research was carried out as one study and all aspects were carried out concurrently, see figure 4.3, which uses pseudonyms. However, for ease of explanation, the research process will be described as two components. Component one refers to data collected regarding the *context* that care takes place – this is about the whole hospital. Component two refers to the data collected about the *cases* – the three wards and the embedded units of analysis, the OPLWD. Both components add to the understanding of the phenomenon being studied: person-centred hydration care for OPLWD in acute hospital wards.

Figure 4.3: Diagram of the study and timeline (NB Figure includes pseudonyms adopted for the cases and units of analysis)



4.6.1.1 Component one: acute hospital context

To understand the context surrounding the case, component one of the data collection involved recruitment of staff who held a leadership role throughout the whole hospital. To be eligible, it was a requirement that as part of their role they had influence on or an overview of the care for OPLWD and/or hydration care within the hospital.

4.6.1.2 Component two: the wards

Component two was the largest part of the data collection and involved recruitment of OPLWD, their relatives and staff from the three wards. The main population studied was OPLWD admitted to the acute hospital. Three linked groups of participants were also included from the wards:

- The multi-professional staff providing care to OPLWD, including the 'hosts' who are the catering staff involved in the process of facilitating drinks.
- Senior staff members with a leadership role on a ward recruited to the study.
- Relatives of the OPLWD.

4.6.2 Participants

The sample was determined by what was required to answer the research questions and explore the issues in depth. It is usual for participant numbers in qualitative studies to be smaller than quantitative studies, where the idea is to produce a generalisable result; conversely qualitative research does not seek to power (Moorley and Cathala, 2019). Prior to recruitment I estimated the number of

participants required in each group to answer the research question and provide in-depth data and managed to meet these estimates. The number of observations, staff and relative interviews provided data saturation (Lacey, 2006) and although formal analysis had not yet begun, through discussion of the data being collected during supervision it was felt there were similar themes arising from the interviews and observations, so data collection stopped at this point. Table 4.5 provides information about the recruitment methods, sampling and inclusion and exclusion criteria.

Table 4.5: Participant sampling method, inclusion, and exclusion criteria

| Participants | Number of participants approached (n=) | Number of participants consented (n=) | Sampling method | Inclusion | Exclusion |
|---|--|---------------------------------------|---|--|--|
| Senior Staff (Hospital Wide) | (n=5) | (n=5) | Judgement sampling, snowballing technique | In a senior and/or leadership position of any professional background, with an expert understanding of key policies, documents and/ or strategies for ensuring quality dementia or hydration care in the hospital. | Their role does not have visibility or influence over the wider structure and processes of the hospital. |
| Senior staff (Ward Based) | (n=5) | (n=4) | Judgement sampling | In a leadership role of any healthcare professional background, with an expert understanding of the key policies, documents and strategies for ensuring quality dementia care in their ward. Likely to be band 7 or above. | They are not in a leadership position on the ward. |
| Older people living with dementia (patients) | (n=21) | (n=14) | Judgement sampling homogenous group | Aged 65-years or older. Have a diagnosis of dementia confirmed, or are being nursed by the ward considering that they have a diagnosis of dementia. Are an in-patient on the elderly care ward, the acute medical unit or the trauma orthopaedic ward recruited to the study | Have identified dysphagia requiring thickened fluids. Require artificial hydration and are not receiving any oral fluid intake alongside this. Are not an in-patient on one of the three wards identified. Are under the age of 65 years. |
| Ward Staff | (n=37) | (n=28) | Judgement sampling | Working on a ward recruited into the study, either as permanent, bank or agency member of staff. From any registered or non-registered health care practitioner staff group including clinical and catering staff. Working directly in any role, for at least one shift, with the patient who is recruited to the study. | They have not worked directly with one of the patients recruited into the study. |
| Relatives | (n=8) | (n=5) | Judgement sampling | Relative or close friend of a patient recruited into the study. Have insight into the patient's usual functioning or preferences. | Unable to take part in an interview face to face or by telephone. Do not speak English. |

4.7 Data collection methods

This section describes and explains the data collection methods used in this research, starting with an overview and rationale. I will then describe how I applied the data collection methods in the setting and any practical decisions taken. Once again when addressing the practical application in the research setting the two components of the study will be discussed separately, although the data were collected concurrently. The data collected for each ward can be viewed in tables 4.6- 4.8.

Table 4.6: Birch participants and data collected

| Ward | Total participants | Leadership Staff member and data collected | | OPLWD Participants | OPLWD data collected | | Staff members and data collected | | Relatives and data collected | |
|--------------|--------------------|--|-----------|--------------------|----------------------|----------|----------------------------------|-----------|------------------------------|-----------|
| | | | | | | | | | | |
| Birch | (n=14) | Ward leaders (n=2) | Interview | Alan | Observation | 8 hours | (n=0) | N/A | (n=0) | N/A |
| | | | | | Fluid charts | ✓ | | | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✗ | | | | |
| | | | | Bill | Observation | 4 hours | Nurse (n=1) | Interview | (n=0) | N/A |
| | | | | | Fluid charts | ✓ | | | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | HCA (n=1) | Interview | | |
| | | | | | Interview | ✗ | | | | |
| | | | | Cara | Observation | 12 hours | Nurse (n=1) | Interview | (n=1) | Interview |
| | | | | | Fluid charts | ✓ | | | | |
| | | | | | Nursing records | ✓ | HCA (n=1) | Interview | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✗ | | | | |
| | | | | Daisy | Observation | 12 hours | Nurse (n=1) | Interview | (n=1) | Interview |
| | | | | | Fluid charts | ✓ | | | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✓ | | | | |

Table 4.7: Elm participants and data collected

| Ward | Total participants | Leadership Staff member and data collected | | OPLWD Participants | OPLWD data collected | | Staff members and data collected | | Relatives and data collected | |
|-------------|--------------------|--|-------------|--------------------|----------------------|----------|----------------------------------|-----------|------------------------------|-----------|
| | | | | | | | | | | |
| Elm | (n= 22) | Ward leader (n=1) | Interview | Eddy | Observation | 12 hours | Nurse (n=1) | Interview | (n=0) | N/A |
| | | | | | Fluid charts | ✗ | St/N (n=1) | Interview | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✗ | | | | |
| | | | | Finn | Observation | 8 hours | (n=0) | N/A | (n=0) | N/A |
| | | | | | Fluid charts | ✓ | | | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✓ | | | | |
| | | | | Gail | Observation | 12 hours | Nurse (n=1) | Interview | (n=1) | Interview |
| | | | | | Fluid charts | ✓ | HCA (n=1) | Interview | | |
| | | | | | Nursing records | ✓ | Physio (n=1) | Interview | | |
| | | | | | MDT records | ✓ | Consultant (n=1) | Interview | | |
| | | | | | Interview | ✓ | | | | |
| | | | | Hana | Observation | 12 hours | DCN (n=1) | Interview | (n=0) | N/A |
| | | | | | Fluid charts | ✓ | Nurse (n=1) | Interview | | |
| | | | | | Nursing records | ✓ | HCA (n=2) | Interview | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✓ | | | | |
| Ivan | Observation | 12 hours | Nurse (n=1) | Interview | (n=0) | N/A | | | | |
| | Fluid charts | ✓ | | | | | | | | |
| | Nursing records | ✓ | | | | | | | | |
| | MDT records | ✓ | | | | | | | | |
| | Interview | ✗ | | | | | | | | |

Table 4.8: Fir participants and data collected

| Ward | Total participants | Leadership Staff member and data collected | | OPLWD Participants | OPLWD data collected | | Staff members and data collected | | Relatives and data collected | |
|------------|--------------------|--|-----------|--------------------|----------------------|----------|----------------------------------|-----------|------------------------------|-----------|
| | | | | | | | | | | |
| Fir | (n=14) | Ward leader (n=1) | Interview | June | Observation | 12 hours | HCA (n=2) | Interview | (n=1) | Interview |
| | | | | | Fluid charts | ✓ | | | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✗ | | | | |
| | | | | Kay | Observation | 12 hours | HCA (n=1) | | (n=0) | N/A |
| | | | | | Fluid charts | ✓ | | | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✓ | | | | |
| | | | | Lily | Observation | 4 hours | St/N (n=1) | Interview | (n=0) | N/A |
| | | | | | Fluid charts | ✓ | Host (n=1) | Interview | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✓ | | | | |
| | | | | Mae | Observation | 12 hours | Nurse (n=1) | Interview | (n=1) | Interview |
| | | | | | Fluid charts | ✓ | HCA (n=1) | Interview | | |
| | | | | | Nursing records | ✓ | | | | |
| | | | | | MDT records | ✓ | | | | |
| | | | | | Interview | ✗ | | | | |

4.7.1 Interviews

In this research interviews were a key qualitative data collection method and the only method used with every category of participant. As the hospital is an environment with multiple people, interviews were suitable as they enable generation of description and interpretation about participants' social worlds (Yeo *et al.*, 2014). Research interviews can be structured, semi-structured or unstructured. Less structured interviews allow a more in-depth exploration of the research topic from the perspective of participants and are helpful to explore a phenomenon where little is known or to understand a context (Tod, 2006, p. 338). In the semi-structured interview, the researcher sets the agenda through the questions asked, although the participant can decide how much information to provide; one risk is that participants may withhold valuable information if the researcher does not ask the right question (Corbin and Morse, 2003). In this research, the phenomenon under investigation was quite focussed, hydration care, so not asking the right questions was not deemed to be too much of a risk and was mitigated by the development of a topic guide. Topic guides were developed to provide information as it related to the concept of PCC. There was room for the participant to shape the discussion through the topic guides being used as a *guide* rather than a structured manual when conducting the interviews. To enable this, I did not follow topic guides rigidly, but memorised the topic areas, enabling a conversational approach to the interview and keeping it close by as an aide memoire (Thomas, 2013). I intended to record all the staff and relative interviews using a digital voice-recording device, however, this was not always possible as some staff declined this aspect, and one relative was only available for an over-the-phone interview, discussed further in section 4.7.1.3.4. Audio recording is beneficial, as it enables the researcher's full presence in the

interview, rather than note-taking, direct quotes can be used in the writing up of research findings, and the researcher can interpret the meaning of words through the tone of voice when relistening (Edwards and Holland, 2013).

When the digital recording device was used, it was placed on a surface close to both the researcher and interviewee. The digital recording device was not used with OPLWD, as explained in section 4.7.1.3.3.

4.7.1.1 *Developing the topic guides*

The topic guides (see appendices 24 - 28) included areas that were important to explore based on the VIPS definition of PCC (Brooker and Latham, 2016). The topic guides with senior staff with leadership roles in the hospital and on the wards (see appendices 24 and 25) focussed on the areas of 'valuing people' in the VIPS Framework, as demonstrated in table 4.2. The ward staff topic guides (see appendix 26) mostly focussed on the areas of individual lives, personal perspectives and the social environment by attempting to further explore the approach to hydration care offered by the staff during the observations. The OPLWD participant interviews (see appendix 27) and relative interviews (see appendix 28) also covered individual lives, personal perspectives, and social environments by discussing the experience and views of hydration care in the hospital but also the routine, needs and preferences the OPLWD had before admission to hospital.

4.7.1.2 Component one: contextual data- Interviews

The topic guide can be found in appendix 24. As I was keen to understand PCC within the hospital context, I provided participants with a copy of the VIPS definition of PCC to read prior to the interview.

As a warm-up question all interviews commenced with me asking the participant to explain their role in the hospital. The interviews varied in location according to the choice of the participant; some participants had access to quiet spaces, but two participants suggested we meet in the hospital canteen, which was noisy at times, however, the seating was spaced out enough that other people would not hear the content of the interviews. The noise level did not impact the digital voice recording.

One surprising aspect of these interviews was that during some interviews, when asking about person-centred dementia care, and hydration, it became apparent that some of the participants were considering hydration from a perspective they had not considered previously, as illustrated in the findings and discussion chapters.

4.7.1.3 Component two: the wards- Interviews

4.7.1.3.1 Interviews with ward leaders

Before collecting any other data on the wards, I organised interviews with a ward leader. This was for practical reasons, as I was in contact with ward leaders to consent the ward. There were additional benefits because these interviews aided my understanding of the ward context which was useful for observations; having established connections with the ward leader was beneficial to my credibility within the environment, which I anticipated would support recruitment. At the start of the interviews, I reaffirmed consent. All these interviews took place face-to-face (my

study data collection was pre-Covid19). I attempted to conduct the interviews in an office, however, there was no office space available to use at the time of interview on any of the wards, demonstrating how little access to a quiet workspace was available for senior nurses. On Birch there was a quiet room for relatives which was available and used. The Elm interview was conducted in a corridor in the hospital and the Fir interview was conducted in a corridor on the ward. Although these environments were not ideal, especially as environmental noise affected recording quality, the alternative was not conducting the interviews. All staff indicated that due to time pressures and their availability, they preferred to complete the interview immediately rather than wait for a suitable environment to become available. None of these interviews were disturbed by other staff or patients, and despite them not being completely private they were in areas where being overheard was unlikely, so although the environments were not ideal, they did not adversely affect the content of the interviews.

These interviews were semi-structured utilising a topic guide (see appendix 25) previously discussed in 4.8.1.1.1. As warm-up questions, I asked the ward leaders questions about the ward such as the size and function which also provided contextual description. This was useful for two reasons: asking factual questions mid-interview can interrupt the flow and introductory questions are a way to establish the interviewer and interviewee roles (Yeo *et al.*, 2014).

4.7.1.3.2 Interviews with staff caring for older people living with dementia

Interviews with the staff caring for OPLWD were sought following an observation period. The interview topic guide focussed on the staff members' knowledge and opinion of the needs of the OPLWD participant who had been observed (see

appendix 26). However, if the staff member provided additional relevant information, these areas were explored too.

I gave participant information sheets out to relevant staff during the observation period and signed consent was gained immediately before the interview; it was important to interview the staff member as soon after the observation period as possible to explore the observational data. The interviews took place in a quiet space on the ward, sometimes in a quiet room, although locating a quiet room was not always possible. One interview was interrupted as a nurse was asked to return to work for an urgent matter. I was unable to complete this interview however the data gathered was used as I had already gained good quality data. Most staff consented to the interview being recorded using a digital voice recorder, however, several staff members in different roles (an HCA, a host, and a doctor) consented for their responses to be documented by me in writing but not to the digital voice recording. The reasons they gave were a lack of time or a preference to not be recorded. I discussed this with my research supervisors, and we felt if a staff member consented to the interview in this format, it was preferable to capture their views rather than to lose their contribution. The interviews which were documented in writing were also different as they took place where the person was situated on the ward and I wondered if the staff member felt their presence was required to be visible in the ward environment, or if this is where they felt most comfortable. I typed up the interview notes immediately and found the staff members on the ward to check my documentation of the interview matched their responses; none of these participants amended the transcript.

4.7.1.3.3 Interviews with older people living with dementia

Interviews were conducted with several OPLWD participants. I utilised my skills from working with OPLWD in a clinical setting as well as considering the work of other authors who had interviewed OPLWD for research. Digby, Lee and Williams (2016) discuss the need for researchers to recognise a person's readiness to talk, facilitate and prompt conversation, create a feeling of safety, tailor the interview to the individual's physical and cognitive abilities, ensure an optimal environment and give the option to include a relative if that is the person's choice.

I was mindful of these considerations when I developed the interview topic guide for OPLWD participants. To account for the potential differences in cognitive abilities I created a topic guide that could be used as a way for the OPLWD to read from, with large writing and symbols, however, this was only used with one of the participants who was struggling to hear. These interviews took on a conversational style. They were different to the other interviews as I did not use a digital voice recording device. This was a deliberate decision to ensure the OPLWD felt as safe and comfortable as possible and to ensure there were no distractions while I was interviewing them. I felt the digital voice recording device may be unfamiliar and not conducive to these aims. I commenced the interview by providing an opportunity for the person to confirm or withdraw consent followed by general 'warm up' questions that were not related to the topic, to develop some rapport. I then followed the topic guide conversationally (see appendix 27) using the paperwork of the topic guide to jot down a few, brief, key points throughout the interview. I feel this approach benefited the interviewee, by providing ongoing orientation that I was conducting a research interview, in which their views and experiences were of value. Throughout the interviews I paid close attention to the body language and responses of the

participants. With one participant I ended the interview early as I noted that they were having difficulty taking part and I did not want to cause them distress.

Once the interviews were completed, I spent further time with the OPLWD in conversation to contribute to a sense of wellbeing. This was also an opportunity for the OPLWD to have time to formulate any questions that may have arisen from participating in the interview, mostly this time was filled with general conversation and me reiterating my thanks to the participant.

4.7.1.3.4 Interviews with relatives

As with the other interviews, these interviews took the form of a semi-structured interview with a topic guide (see appendix 28). I gained each relative's consent prior to the interview and then conducted the interview face-to-face with a digital voice recording device, except in one case, where the relative preferred to complete the interview over the phone. I made notes and shared them with each relative once I had typed it up for any errors - they did not make any amendments.

4.7.2 Documentation

Documentation can be defined as "a human artefact that contains information" which may include paperwork containing writing, diagrams, drawings, or may be computer files (Alaszewski, 2012, p. 67). In healthcare research the use of documentation may include patient records, which were used for this research. These documents provide information about the nature of health issues, rather than an understanding of the individual's *experience* of the health issues (Alaszewski, 2012). Documentation is a type of data with relevance to most case studies (Yin, 2014, pp. 105-106). Clarkson (2003) reminds the researcher that documents tell us what the author wants to express, rather than what the researcher wants to know; it is

necessary to pay particular attention to the context within which the document exists and why it was created. The use of the documents was deemed necessary based on my prior knowledge, that clinical information is documented, and was also a finding of the literature review. Documents were also used to support and clarify the evidence collected through other methods, contributing to triangulation of the data and rigour, as discussed in section 4.4. By viewing policies and the professional, clinical documentation and communication related to hydration care for OPLWD, documents also illuminated the context of care. Documentation was also beneficial as it did not intrude on the time of participants and access was simple to facilitate. Prior (2003) argues that researchers may tend to value the spoken word over documentary data, possibly because the interviewer cannot influence the documentation in the way they can in an interview process, with flexible exploration of a topic. This demonstrates one weakness with documentation: that a deeper understanding of the author's intentions cannot be elicited through direct questioning. It is also positive that researchers cannot exert bias over the data or influence the document, for example the healthcare documents in this study existed prior to the data collection. However, in my study I was able to broadly scrutinise a document author's general views on clinical documentation through the interview data.

4.7.2.1 Component one: contextual data- documentation

I planned to obtain and analyse specific policies and strategies relating to the hospital's hydration and dementia care. The hospital did not have any strategies or policies published relating specifically to dementia although I was informed one was in development; absence of a dementia policy itself was noteworthy. The nutrition and hydration policy was available but outdated, and found through a search rather

than identified by participants. The Carer's policy was also identified as having relevance to OPLWD. Copies of these policies were obtained and analysed. The policies were accessed through the local intranet system, to which I had access.

4.7.2.2 Component two - ward data documentation

The documents relevant to this component were clinical records. Clinical records are an important aspect of multi-disciplinary working in hospitals and provide ongoing records of an OPLWD's journey in a clinical setting. For this reason, it was important to the study to analyse the information within these records.

Retrieval of these documents was simple, as the documents were kept in the ward. I used two data extraction tools (see appendices 29 and 30), which I developed, to extract the relevant information from the nursing records and the multi-disciplinary clinical records. I extracted the documentary data following my observations. Prior to accessing the clinical records, I informed the nurse looking after the patient that I would be using the records and checked that it was not an inconvenient time; this was to minimise any impact on their work and ensure transparency.

I also asked the ward leaders if they felt there were any policies or guidelines that were relevant; there were no further policies identified at this stage.

4.7.3 Direct observation

An underlying principle of PCC is the importance of relationships and social interactions to support personhood, avoiding malignant social psychology (Brooker and Latham, 2016; Kitwood, 1997), which was explored in sections 3.2.1 and 3.2.2. To understand the social interactions, direct observation of interactions was required.

Observation as a form of data collection observes people in the real-world setting of the case and may be called fieldwork (Yin, 2014). An observer's role can be anywhere on the continuum from the complete participant, the participant as observer, the observer as participant or the complete observer (Gold, 1958). In this study I was 'the observer as participant' as I was participating through presence in the location but was not part of the workforce. Despite being present as a researcher I also had obligations as a registered nurse in this environment.

Observation felt methodologically suitable and, from an ethical perspective, it does not place too much burden on the OPLWD participants; it has also been used successfully in other hospital studies with OPLWD (Cowdell, 2010; Porock *et al.*, 2015; Sampson *et al.*, 2019). Observation also contributed to the rigour of the study through triangulation of data. As this study was examining a phenomenon in its real-world context it was also important to see what healthcare staff actually do, compared to what they say they do (Watson and Whyte, 2006). Watson and Whyte (2006) explain that, used alongside other data collection methods, observation can confirm or support data, reducing the bias which may be received from interview participants giving socially acceptable answers or not being able to recall events accurately. There is also the ability to view mechanisms of an organisation and

behaviours that participants may not be aware of themselves (Furlong, 2013; Morgan *et al.*, 2017)

To conduct the observations, a data extraction document was developed (see appendix 31), which allowed for the combination of unstructured field notes and structured observations by utilising a recognisable observational tool, the Quality of Interaction Schedule (QUIS) (Dean *et al.*, 1993), and additionally the flowchart developed by McLean *et al.* (2017) was used to check the rating during the observation and confirmed when typing up the observation electronically.

The QUIS rates the interactions between staff and older people; it was developed for use with in residential settings that provide care to adults with severe mental illness. The interactions are rated by providing a rating of positive social, positive care, neutral, negative protective and negative restrictive (Dean *et al.*, 1993). Although it has since been used successfully in hospital settings (Barker *et al.*, 2016; McLean *et al.*, 2017). The aim of QUIS ratings was to demonstrate that there are important distinctions between the types of positive and negative interactions encountered by older people. The use of a tool to structure the observation can minimise observer bias (Watson and Whyte, 2006). The structured observations using QUIS capture time stamps, number of and lengths of interactions, and ratings, which made up a quantitative element of the study, which was supportive to the qualitative data. The quantitative results from the QUIS would not have been adequate to provide the depth required to understand the phenomenon, so qualitative field notes were also used to support the QUIS data. The first participant, Eddy, was used to pilot the data extraction tool and minor amendments were made to the useability of the tool by increasing the space for documentation and a decision made to record the times to the nearest 30 seconds.

All interactions between staff and OPLWD, including non-hydration related interactions, were recorded, along with hand-written field notes. The only interactions that were not rated were interactions that took place behind the curtain. It was felt this would be an unnecessary intrusion into the care of the participants and not essential to the research aims, as it was unlikely to be where the main hydration care took place. I chose to hand-write contemporaneous field note observations, as this provided reassurance that I was capturing what was happening. Other researchers support writing fieldnotes once an observation period has ended (Wolfinger, 1995).

One concern conducting observation in any setting is that people being observed may change their behaviour due to being observed; this is called “The Hawthorne Effect” (Payne and Payne, 2004). However, my experience resembles that of Mulhall (2003) who felt that professionals were too busy to maintain behaviour very different to their usual pattern. I felt that quite soon after an observation began there was little attention paid to my role, as I witnessed behaviours by staff which I believe they knew were substandard, such as closing their eyes or being on their phones when they should have been providing direct care to OPLWD, despite being aware of my presence as an observer. I do not think they deemed me someone they needed to make modifications as I observed they changed these behaviours when senior staff were present.

4.7.3.1 Component two: the wards- direct observation

The observations took place for four hours, between one of the time frames: 8am-12pm, 12pm-4pm or 4pm-8pm with an aim to reach the full 8am-8pm period for each participant. This was not always possible due to patients being discharged or moved to a different ward. Initially, I planned to observe from 7am-10pm but was informed by a ward sister that the 8am-8pm timescale would be more acceptable, as these

were more likely the 'waking' hours and it would be less disruptive to introduce myself to the day staff prior to an observation, rather than disturb the night staff at a busy time of their shift. Following this advice, I decided to use the recommended times for all wards, to facilitate comparison across the cases. At the edge of the bays on all wards was a raised area with a worksurface, often with a computer, and this is the area I usually placed myself for conducting the observation.

Before the observations, I explained my role as a researcher to the staff and that I would be observing. I later added in that I was not in a place to provide care as I experienced several occasions when staff had asked me to "keep an eye" on the OPLWD. I found that even when I explained that I was not able to provide any care that staff occasionally still requested this of me. Similar circumstances have taken place in other healthcare research, with Turnock and Gibson (2001) labelling their role as nurses in a setting they were familiar with as being, 'quasi-insiders.' Similarly, they reflected that they felt they could not refuse staff using them in this way, as the request was often rapid and for a short period of time; they also reflected that patients probably benefited from this in some ways. I felt that there were times when information I acquired from these moments allowed me to advocate for the patient's care as the conflicting priorities of being a nurse, following a professional code of conduct (NMC, 2018), outweighed the need to be a passive observer conducting research. This provides examples of when qualitative researchers need to consider if they are an insider or an outsider and any impacts this may have.

Being an insider or outsider to the area of research is an issue within qualitative research, where the aim is to gain an in-depth understanding, as it has implications for the researcher's understanding of an area and their potential bias about this. Whilst there are benefits to either being an insider or an outsider, such as better understanding of a population, or concerns about a researcher's objectivity, it is

important to be aware of your position through self-reflection to avoid unintended bias (Corbin Dwyer and Buckle, 2009). As discussed in section 1.3, I did not consider myself a true insider, however, to the hospital staff as a registered nurse, with an honorary contract, and therefore an identity badge to the hospital, I may have been considered an insider and I also recognised I was not wholly an outsider. The work of Corbin Dwyer and Buckle (2009) emphasises that it is over simplistic to present insider and outsider as being binary and they consider that researchers occupy the space between insider and outsider. I identify with their view but also recognised my position required ongoing reflection, which I achieved through unstructured contemplation about my research experiences and in structured documentation in a research diary, as well as discussions during research supervision.

Prior to the observation period I had considered when I would intervene if someone's safety were compromised; I based this decision on whether I felt harm may come to the person I was observing if I did not intervene. I did intervene on several occasions for psychological distress that I felt was harmful, as well as potential physical harm from a fall, which was similar to other nurse researchers' experiences (Conroy, 2017). I then recorded this as part of my field notes. One aspect I had not considered greatly was the emotional labour involved in observing care which left the person with unmet needs, but was not causing obvious or immediate harm, and did not necessitate my intervention. I found the use of a research diary useful to document these emotions, however, these emotions sometimes resurfaced during the analysis of the observational data and the use of supervision was beneficial to discuss these thoughts.

4.8 Mixing methods

The data collection process captured qualitative data from multiple methods and an aspect of quantitative data through the use of the QUIS observational tool (Dean *et al.*, 1993). In this way the study could be considered mixed methods research, which combines both qualitative and quantitative research and is regularly aligned with the pragmatic paradigm being used. However, this study was never conceptualised as a mixed methods study, as case study methodology can accommodate multiple methods, without labelling the research a 'mixed methods' study. However, there are benefits to considering the principles of mixed methods research, particularly when considering how to address the integration of the multiple methods of data collection. The use of mixed method literature is used only to support the discussion about integration in section 4.9.3. For the analysis I discuss the qualitative and quantitative analysis as separate sections, as they used different techniques and tools to analyse, which are discussed in the next section. A separate section 4.9.3 discusses the integration of the data.

4.9 Data analysis

Within case study there is not one prescribed way to analyse data but there are recommended strategies to use which draw on established analysis techniques (Yin, 2014, pp. 132–170). The qualitative and quantitative data required different approaches. Qualitative research produces a large amount of verbatim data, and requires the researcher to develop structure and a coherent narrative from the data whilst continuing to provide a reflection of the original accounts. This requires the principle of detection, using defining, categorising, theorising, explaining, exploring and mapping to go about the 'detection' (Ritchie and Spencer, 1994). There are a variety of qualitative analysis techniques which can be used for qualitative data. In

this research I used the analytical process developed by Ritchie and Spencer (1994), which is known as 'framework.' The quantitative analysis will be discussed in section 4.9.2.

4.9.1 Qualitative data analysis: framework

Once the data were collected, an analysis protocol was developed to guide the process, explaining the steps of framework, which was developed by the qualitative researchers, Ritchie and Spencer (1994). As well as providing recognised steps for data analysis used in other qualitative analysis, it has an additional step which is data summary and display within a matrix. This approach was felt to be particularly useful for a multiple case study, as it would enable data to be viewed across the cases and within the cases. The approach was developed in applied social policy research which usually generates data to find answers to problems in a short space of time, with multiple team members required to view the process, discuss, review and ensure transparency for funders. Framework is gaining popularity in healthcare research, with the benefits that it enables systematic analysis of qualitative data (Smith and Firth, 2011) and is a transparent method (Furber, 2010) which enhances rigour (Ormston *et al.*, 2014). The approach to rigour in data collection and analysis in this research was discussed in section 4.4; table 4.9 expands this by adding how rigour applies to the framework analysis.

Table 4.9: Approach to rigour; application to research and framework

| Approach to rigour | Techniques that apply the approach | Application to this research | Application to framework |
|---|---|--|--|
| Credibility | Prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, member checks | <ul style="list-style-type: none"> • 132 hours of observation. • Triangulation (observation, interviews and documentation analysis). • Quantitative data to enhance qualitative findings. • Identification of 'outlying' pieces of data. • Regular discussion with supervisors. | <ul style="list-style-type: none"> • Ability to collaborate and show decision making. • Allows easy retrieval of data from original sources. |
| Transferability | Thick descriptive data | <ul style="list-style-type: none"> • Description of setting. | <ul style="list-style-type: none"> • Able to manage a large amount of data. |
| Dependability and confirmability | External audit, audit trail and an external auditor | <ul style="list-style-type: none"> • Process of research documented in thesis • Transparent analysis strategy. • Use of participants own words when presenting findings. | <ul style="list-style-type: none"> • Ability to show step-by-step decision making process. |
| Reflexivity | Critical self-reflection | <ul style="list-style-type: none"> • Research diary kept-including reflections prior to data collection as well as during data collection. | <ul style="list-style-type: none"> • Dynamic technique allowing for change and amendment. |

Framework has five key stages, however, Gale *et al.*, (2013) suggest additional steps for multi-disciplinary health research. I have compared these approaches in Table 4.10. I used the approach documented by Gale *et al.*, (2013) as I found the breakdown of stage 1: familiarisation into three aspects, in addition to the accompanying description provided in their article beneficial for when I practically used the approach for analysis.

Table 4.10: Stages of framework

| Stage | Ritchie and Spencer (1994) | Gale <i>et al.</i> (2013) |
|-------|---|---|
| 1 | Familiarisation | a) Transcription b) Familiarisation c) Coding |
| 2 | Identifying a thematic framework | Developing a working analytical framework |
| 3 | Indexing the data using the framework | Applying the analytical framework |
| 4 | Charting the data in themes and subthemes | Charting data into the framework matrix |
| 5 | Mapping and interpreting the data | Interpreting the data |

Another benefit of framework relevant to this research is that it provides a strategy to manage a large amount of data. Framework can be used with or without computer-aided qualitative data analysis software (CAQDAS). I chose to use the CAQDAS, NVivo12 as I was familiar with it and found it invaluable to manage the large data set. Although framework has similarities to other qualitative analysis approaches, using coding and sorting of data to develop themes, the unique aspect is the matrix – providing data summary and chart display. The ability to chart data fits well with the case study methodology used, as it allows exploration of the depth and breadth of the data, and a systematic approach to exploring the findings from across and within the cases. Framework also fits well with using a theoretical framework, allowing the use of an a-priori framework to enable deductive and inductive themes to be captured.

4.9.1.1 Stage one: Familiarisation, transcription and coding

All the data were collected and transcribed by me between January and August 2018. Data analysis began in April 2019, which was approximately eight months from the date of the last data being collected and transcribed; this meant the data

had become unfamiliar. To re-familiarise myself, and aid analysis, I listened to all audio data again while checking transcriptions for formatting and accuracy. Initial thoughts and impressions were recorded at this time. At this stage, each ward and participant was given a pseudonym. I found this enabled me to view the OPLWD as a person again, rather than a unit of data.

Familiarisation

The data set is large, with four separate aspects: contextual data, and each of the three wards (cases) and their embedded units of analysis. To begin, I focussed on the contextual data. Sequentially, I then familiarised myself with the cases to ensure each case was viewed separately from other cases; this was also a beneficial system to practically manage the large data set.

The research questions were revisited briefly, however, the aim of familiarisation was to look broadly at what was emerging, not to be too guided by the questions being answered. I read and re-read the interview transcripts, fieldnotes and clinical documentation in their entirety and documented initial thoughts in a notepad or directly onto the transcript. At monthly supervisions, emerging thoughts were discussed with supervisors as part of the analysis process.

Coding the data

Following familiarisation, I entered the interview transcripts, fieldnotes and clinical documentation onto NVivo12. I had previously undertaken an NVivo training course, however, at this stage I spent time refreshing my use of the software by watching tutorial videos and reading user information guidelines.

Once the data were organised in NVivo, the VIPS Framework (Brooker and Latham, 2016) was revisited. As this definition of PCC had been used to develop the research

questions and data collected, the categories of this framework provided a-priori codes to be used. The a-priori codes were added to NVivo12 before the coding commenced; new inductive codes were added throughout the coding of the interviews if they did not fit in with the a-priori coding. I also referred to the original thoughts documented in the familiarisation stage to aid the coding. I continued to keep notes as new thoughts developed during the coding process; these were recorded on NVivo's memo function. Additionally, I continued to make handwritten notes, as the process of writing aided my thinking. The same process was then applied to each case.

4.9.1.2 Stage two: Developing an analytical framework

Once all transcripts, fieldnotes and clinical documents were coded, I spent time scrutinising the coded transcripts against the research questions. The codebook was reviewed, and similar codes were combined into categories to develop a working analytical framework. Explanations of the categories were documented within the "Node" section on NVivo.

I then applied the working analytical framework, one participant at a time to check if the framework fitted, or if additional codes were required. New codes were added at this stage, as they emerged from the data or the impressions documented during the familiarisation stage. For the MDT and patient records, summaries and occasionally impressions were written on the document which was then coded into the analytical framework.

An example of an MDT record is copied in Table 4.11. The summary that was written was:

"She has had poor intake for 5 days and a pressure ulcer- medics do not discuss the low nutrition and hydration in their documentation. Nursing documentation does not flag up any specific intervention need. Wording

around nutrition and hydration is not very descriptive, "as able" or "fairly taken." Also, it is documented she was "eating and drinking well" on the 19th which doesn't match with the fluid chart."

The summary was coded and added to the category in the analytical framework, "documentation." Other relevant aspects of the MDT records were coded also, for example the discussion of "IV fluids" were added to the category, "clinical hydration" on NVivo.

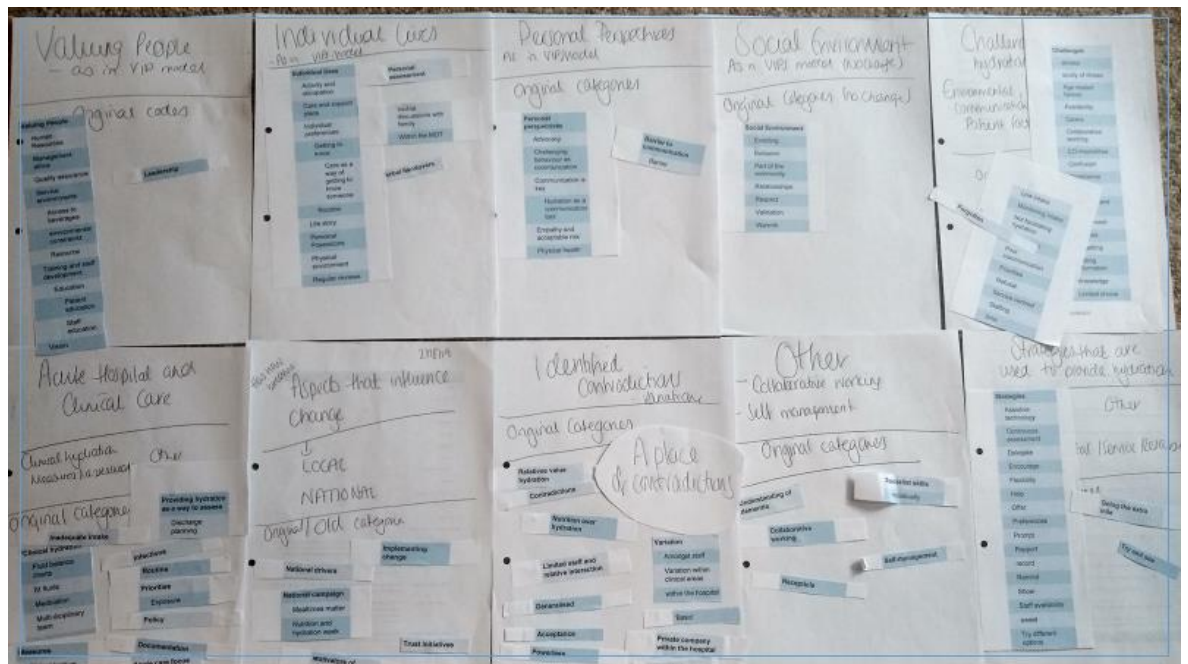
Table 4.11: Example of MDT record

| | |
|--|--|
| <p>Medical (ward round) What has been written? What date? Which profession and grade recorded it? Any care plans created? Any referrals?</p> | <p>20/6/2018- Treated as UTI in ward round today and yesterday, no discussion of fluids on this admission however IV fluids commenced.</p> |
| <p>Medical (other) [See above for prompts]</p> | |
| <p>Nursing What has been written? What date? What is the nurses' role/banding? Any care plans created? Any referrals?</p> | <p>15/6/2018 "19.30- IV fluids" (RN) "16/6/2018 P- IVF, IV abx, analgesia, laxatives" (staff nurse) "16/6/2018 A- Incontinent, BO x1, E&D with encouragement +++, occasionally self-positioning and turns with assistance, bladder scan 271 mls, sitting and lying BP done." 17/6/2018- no fluid mentioned on 17/6/2019, main documentation is around grade 2 pressure area. "17/6/2018 day report A- assisted with her meds, drinking and diet fairly taken, ulcer wounds to be discussed" "18/6/2019 19.30- E&D small amounts (1st and 3rd to Left +ve ulcers, doubly incontinent) hoist transfer, A- Paid, falls, delirium, UTI, decreased PO intake, I/E -all due meds and PRN analgesia given, patient assisted with hygiene needs and regular repositioning, keeps moving feet and unsettled in bed due to increased pain, oral intake encouraged as able, vital signs and CBG monitored patient clean and dry, daughter present " (staff nurse) 19/6/2018 5.30am "all due medications given as prescribed with a lot of encouragement. Eating and drinking well." 19/6/2018 19.20 "O-NEWS= 0, CBG= 11.4, E&D as tolerated, G2 on sacrum, G1 on heels, ischaemic ulcers on toes, doubly incontinent, hoist transfer, Right hand PVC in situ, U/P= 0, BNO yet. I/E – Due meds given, PRN analgesia every couple of hours due to increased pain in foot and legs, assisted with personal hygiene needs, hoisted into chair for couple of hours ,, toes ulcers dressings changed, team spoken to daughter, DNAR now in place, oral intake encouraged as able, patient regularly repositioned – kept clean, dry and comfortable, pain managed as able." (staff nurse)</p> |

4.9.1.2.1 Refining the analytical framework

Once several participants were coded across the wards, the analytical framework was formally reviewed and refined, 139 codes were reviewed to find overlapping or similar categories to create a refined analytical framework. To do this all codes were printed and laid out onto a large piece of paper as a visual display, so that they could be moved around and combined, see figure 4.4.

Figure 4.4: Coding process



At this stage I checked the descriptions attached with each code and if it was unclear, checked how it was used by reviewing the original transcripts and coding on NVivo. Following this process, a refined analytical framework was developed which consisted of 47 codes in 11 categories.

4.9.1.3 Stage three: Applying the analytical framework

The next stage was applying the framework to the data for the remaining cases. No additional categories were developed, however, some additional codes were created. NVivo was used throughout this process, enabling constant checking of original data materials while applying the framework. Although the steps have been

discussed sequentially, the qualitative data analysis was conducted through an iterative process. Once I had applied the analytical framework, I wrote a summary of the findings from the initial categories and findings from the case, which I revisited in stage five.

4.9.1.4 *Stage four: Charting data into the framework Matrix*

The next stage is to chart the data. The first stage of charting the data is creating a chart with the categories and codes from the analytical framework in one axis and the source of the data in the other axis. Using NVivo there is a function on the software to create a “framework matrix”, which enabled me to select codes and sources of data to be pulled through into a chart. This function was used and then the chart was exported from NVivo into Microsoft Excel, which I found beneficial for the next part.

To complete the charting the coded data needed to be condensed into summaries, which made it more manageable and benefited readability, however care was taken to retain the original meaning when writing the summaries. I started this process and once again worked through contextual data and then case by case sequentially. Important quotations were kept with the summaries in the chart, if they were felt to be relevant to illustrating the summary.

4.9.1.5 *Stage five: Interpreting the data*

This was one of the most challenging phases of framework analysis and involved intense consideration of the data set. Ritchie and Spencer (1994) recommend at this stage that the key features of qualitative analysis (see table 4.12) are considered, as well as the aims of the study and the research questions.

Table 4.12 Features of qualitative analysis

| Feature of qualitative analysis |
|---|
| Defining concepts: understanding internal structures |
| Mapping: the range, nature, and dynamics of phenomena |
| Creating typologies: categorising different attitudes, behaviours etc |
| Finding associations: between circumstances, attitudes, and behaviours etc |
| Seeking explanations: explicit or implicit |
| Developing: new ideas, theories, or strategies |

Adapted from (Ritchie and Spencer, 1994)

At this stage I divided the contextual chart data from the case chart data. Starting with the case data, the charts were reviewed, across case themes and within case themes and I revisited the aims, objectives and research questions. I began to seek explanations from within the data. This stage involved creativity and imagination, to tell the story. I presented the findings in a narrative format and they make up the findings chapters. I also used the findings from the quantitative data at this point to complement the narrative, contributing to the integration which is discussed in section 4.9.3. Additionally, a typology of roles was created, presented in the findings section 5.4, table 5.2 and explanations were provided through figures 7.1, 7.2, 7.3 in the discussion section. The quantitative data analysis is discussed in the next section.

4.9.2 Quantitative data: Statistical Package for Social Sciences and descriptive statistics

Quantitative data were collected using the QUIS (Dean, Proudfoot and Lindesay, 1993). This provided numerical data such as length and number of interactions, as

well as non-numerical data such as the gender of the participant, which staff member the interactions were with, and the rating of the interactions.

To analyse this quantitative data a statistical software was used, Statistical Package for Social Sciences (SPSS) version 25, as this was available for download through the university library. I had not used SPSS previously so several books (Greasley, 2008; Pallant, 2016; Wagner, 2013) and a meeting with my supervisor provided guidance.

The first stage was to prepare the data for input to the database, which allows the data to be analysed. To do this all data requires to be entered as a number. A codebook was developed to assign a numerical code to all aspects of the data: the length of interaction, who the interaction was with, the QUIS rating and if the interaction related to fluid, how it related to fluid.

The coding from the codebook was then applied to the observational data, to ensure all numerical and non-numerical data had the correct code applied; this was checked several times for accuracy.

The codebook was added to SPSS using the variable view function and descriptions of the type of data were added alongside the measure of the data and whether it was scale, nominal or ordinal data. Once the codebook was added into SPSS and the raw data had the code applied the data were entered into SPSS using the data view. Each observation period for each patient participant was entered separately until all participant and observation periods were entered onto SPSS; data were cleaned and checked before analysis and there were no missing data in the data set. The data analysis was first run for the frequencies of data which provided a way to check that no data had been missed when it had been inputted. The data input to

SPSS was checked to ensure it was entered onto the software in line with the raw data. This contributed to the data cleaning and management process.

For this study, it was necessary to produce descriptive statistics to add which could be used alongside the qualitative findings to compare alongside the observation and interviews to provide further exploration of the phenomenon of hydration care for OPLWD in acute hospitals.

To produce the relevant descriptive statistics, the data were analysed using the descriptive statistics option on SPSS and a variety of variables were entered for crosstabs comparison, frequencies, sums, and percentages. Where there was benefit in aiding the understanding of the data within the crosstab function cells were selected to show percentages alongside frequencies. This produced tables which were reviewed for findings, exported and saved. The tables were then added to the findings chapter to be presented alongside the qualitative narrative findings, enabling further analysis of the phenomenon of person-centred hydration care for older people in acute hospitals.

4.9.3 Integration of data

High quality analysis requires:

1. Using all the evidence
2. If possible, addressing all rival explanations
3. Addressing the most significant aspect of the data
4. Using your prior expert knowledge (Yin, 2014, p. 168)

To use all the evidence requires integration although Yin does not use this terminology, using the terms convergence or non-convergence of evidence (Yin, 2014, p. 121). Convergence of multiple methods, or integration - the interaction between the qualitative and quantitative data - is given particular attention in mixed methods research methodological discussions (O’Cathain *et al.*, 2010). One

technique for integrating the findings is triangulation, for which different definitions exist, although it is generally regarded as combining research strategies which include methods, sources, theories and/or investigators to achieve a multidimensional view of the phenomenon (Farmer *et al.*, 2006; Foster, 1997; Yin, 2014). In my study, method triangulation was adopted through multiple sources of data and data collection methods. Using triangulation to consider the interaction and conversation between the different methods can demonstrate relationships which are convergent, in agreement, complementary, have different perspectives on the same phenomenon, or are dissonant/ divergent, that is contradictory (Erzberger and Prein, 1997). Triangulation was assisted using framework which enabled the results from multiple sources of data to be viewed across categories using charting. The qualitative and quantitative data were collected concurrently and then analysed separately. The main integration was at the interpretation phase, while creatively making sense of the research questions to present the findings and answer the research questions. The triangulation relationship was to offer data which were complementary to one another, to contextualise hydration care for OPLWD in acute hospitals. As explained above, the data were integrated at interpretation, so the qualitative and quantitative findings are presented together. These findings are presented in the next two chapters.

Chapter summary

The methodology chapter has presented and justified the use of case study methodology to answer research questions which seek to explore hydration care for OPLWD admitted to an acute hospital utilising the theoretical framework of PCC. The chapter presents the practical decisions made when gaining access to conduct research within an acute hospital and its wards as well as the ethical considerations

required when conducting research with participants who have a cognitive impairment and the steps taken to enable participation in line with the legislation.

Throughout the chapter, the theory relating to the individual research data collection methods of interviews, observation and documentation were addressed, with discussion on how this was applied in the research setting with staff, OPLWD and their relatives. The management and framework approach to the qualitative and quantitative data was explained through the final sections, including discussion of the CAQDAS used for both types of data. Finally, the chapter explained how the data were integrated through interpretation, which is explored in chapter eight. The next chapter presents the first part of the findings.

5 Findings: setting the scene for hydration care- hospitals, wards and roles

5.1 Introduction

This chapter provides findings to three research questions, which are displayed in table 5.1 with the themes and subthemes.

Table 5.1 Research questions one, two and three: themes and subthemes

| Question | Theme | Subtheme |
|--|--|---|
| 1. How does the acute hospital affect person-centred hydration for older people living with dementia (OPLWD)? | The acute hospital: hydration is an obscured aspect of care | National drivers: <i>“National initiatives...they’re what the organisations really grab.”</i> |
| | | Dispersed locally: <i>“We’ve got small strategies going on in different areas”</i> |
| 2. How do ward environments affect person-centred hydration care for OPLWD? | The wards: hydration is overshadowed at ward level and partly obscured from healthcare staff | Other aspects of care are valued more than hydration: <i>“I am 1:1...because of the risk of pressure sores”</i> |
| | | A physical barrier to hydration care for healthcare staff <i>“before ward sisters could get into their own kitchen”</i> |
| | | Hydration is routinised to an outsourced worker; it is not part of the healthcare staff’s routine: <i>“When the tea comes you can have one”</i> |
| | | Views on dehydration: <i>“Dehydration is not good”</i> |
| 3. How do staff view their roles related to hydration care and how does this compare with observations of hydration care? | Whose role is hydration care? | Is hydration care everyone’s role or no one’s role? <i>“Anybody going past can offer a drink”</i> |
| | | Training, knowledge and staffing: <i>“There’s a variety of experience and knowledge throughout the MDT”</i> |
| | | The siloed nature of hydration care roles: a typology |

The findings which answer the first question provide an overview of how hydration and dementia care are situated within the acute hospital context, through the interviews conducted with staff members who held hospital-wide roles. The theme demonstrates how external, national drivers influence the hospital organisation agenda. Implementation of the agenda is then discussed in section 5.2.2, highlighting that hospital-wide staff feel that a hospital-wide strategy for hydration care is lacking. Section 5.3 introduces findings from the interviews with ward staff and observational data to describe how ward-level hydration care is influenced by the organisational agenda. The chapter closes with theme 5.4, which poses the question of whose role is hydration care? A typology of individual roles are presented, demonstrating they are diffused and compartmentalised. There are also discussions of staffing more broadly, demonstrating that existing knowledge, skills and training do not support hydration care and staffing issues are complicated by staff contracts.

5.2 The acute hospital: hydration is an obscured aspect of care

This theme presents the hospital organisation's view of hydration and dementia care. Areas of care with a national profile, measurement or incentive were most valued. Hydration care did not have a national profile, therefore it was not viewed as a significant priority. This influenced its place with competing priorities of the hospital and a strategy for hydration care was not fully developed, so work relating to specific populations, such as OPLWD were not developed. When strategies were implemented, they were unevenly dispersed through the individual wards. Hydration was linked to nutrition with a focus on nutrition and mealtimes which did have a national profile. There were limited ways for feedback about hydration care for OPLWD to be shared from a ward-level to hospital leadership.

5.2.1 National drivers: "*National initiatives...they're what the organisations really grab.*"

A key finding was that forces external to the hospital had the most influence on organisational priorities that influenced care. Topics with national profiles, often through initiatives or campaigns, strongly determined where the hospital leadership focussed resources for change implementation or quality metrics. Hydration has not had a national profile or a national campaign:

"Nationally [...] we've focused on protected mealtimes [...] but we've never had so much of a push on making sure your patients - and staff - are hydrated. [...] I mean the national initiatives, national campaigns [...] they're what the organisations really grab [...] you look at "Stop the Pressure" campaign "Protected Mealtimes" "End PJ Paralysis" [...], but I can't think that we've ever had... [a campaign about hydration]" (Hospital Wide Staff (HWS) 4, interview.)

Priorities may have been linked to a document of national importance:

"Dementia becomes important because it's got a national profile [...through] 'The Prime Minister's Challenge' [document...] we know that the CQC is looking at it so when you've got big drivers [...and] people coming in asking you about your dementia care, then it gets the top table interested." (HWS2, interview.)

Priorities may have been determined by national organisations which the hospital was mandated to adhere with:

"Having a nutrition steering group is one of the requirements of the hospital food standards, which are now mandated by [NHS Improvement] who sit under NHS England [...] also, [...] nutrition and hydration is something that is looked at by the CQC [...] So, having a nutrition and hydration group is kind of mandated, it's something that all Trusts have to do." (HWS5, interview.)

Priorities may be linked with national quality metrics, audits, or financial incentives, such as a Commissioning for Quality and Innovation framework [CQUIN]:

“CQUIN was a big driver [...] because it had money attached to it and it said: “you need to deliver this or we’re going to take this money away” [...] that’s when we got our [dementia] team” (HWS2, interview.)

There was awareness amongst the hospital-wide participants that external, national drivers influenced decisions and priorities made by organisational leadership. Overall, the participants viewed this as improving care standards but there was gradual realisation that certain areas of care, including hydration, may then be overlooked:

“If you look at all your quality metrics, we focus as organisations [...] on outcomes for patients. So, we have a massive push on pressure ulcers, falls with harm, sepsis, deteriorating patient [...] we’ll lead a big, big project and we’ll achieve what we need to achieve to reduce pressure ulcers [...] but I just don’t think we’ve ever really sat down and thought well, where does hydration come into all of this?” (HWS4, interview.)

National drivers and external forces substantially influenced the focus of the acute hospital organisation, however, hydration care became an overlooked priority. The next section will discuss how strategies are implemented locally.

5.2.2 Dispersed locally: “We’ve got small strategies going on in different areas”

Hospital-wide staff perceived that developing a hospital-wide group was considered requisite to implementing strategies at a local-level but that strategies were decided, implemented and prioritised in various ways. There were two relevant hospital-wide groups for hydration or dementia care: the Nutrition and Hydration Strategy Group (NHSG) and the Older Adults Team (OAT). The OAT led on older people’s care,

including dementia, across the hospital. However, formation of a hospital-wide group did not guarantee the area of focus would be valued or strategies delivered successfully throughout the hospital. It was acknowledged that the NHSG covered an area of 'mandated' care, but to be valued or to successfully implement strategies required buy-in from senior managers:

“The main things are the food and drink strategy, which is a big overarching piece of work, [...] really needs to be [...] signed off and bought into by the Chief Nurse and Chief Execs, so it needs to be that kind of high level and then we will have a work stream going on under that.” (HWS5, interview.)

The issue of 'buy-in' was echoed and expanded in another interview, stating that if the objectives were captured by another HWG with a higher profile, in this example 'quality and safety,' this could have a positive impact on the success of the topic:

“One of the biggest challenges [...] is that we are currently trying to push both nutrition and hydration - as a priority and agenda for the trust. So, I took a paper to the quality and safety [group...] around 'where are we in relation to nutrition and hydration- as a strategy?' 'What's our strategy?' [...] we haven't got one. 'How do we engage people?' We have limited engagement across the organisation. So, we have good engagement from our dietetics team, [...] but we've had, sadly a lack of engagement from nursing colleagues, from facilities colleagues, we've had some medical engagement but not as much as we would probably hope for [...] what I flagged was that I think our whole strategy around nutrition and hydration both for patients and for staff, we have not given it enough of a priority on the agenda for the organisation and that's truth.” (HWS4, interview.)

Although it was reported there was no nutrition and hydration strategy and no participants discussed the nutrition and hydration policy, there was a nutrition and hydration policy within the hospital. However, the main objectives included in the nutrition and hydration policy were nutrition, malnutrition and mealtimes. Among the

participants it was felt that a lack of a whole-organisation approach and strategy to focus on improving hydration care hindered the ability of the HWSG objectives:

“So, we've got small strategies going on in different areas, [...] but we just haven't [...] got our overarching nutrition and hydration strategy [...] we recognise that that's an issue and hence we're trying to involve the quality and safety [group] and put it up really high on the agenda.” (HWS5, Interview)

As well as varying engagement from different professions, it was identified that even within an HWG with a specific focus there could be a lack of motivation or engagement from participants at all levels required to make changes. Additionally, goals amongst the HWG's membership may differ:

“The catering lead for the trust [...] does sit on the NHSG, I've been to quite a few of the meetings and I haven't seen [them] there [...] currently, from [their] perspective [they] want to reduce the number of 'enhanced beverages' as they call them, like juices etc, on the wards. And we're like "no don't do that," [...] they see it as a cost-saving initiative, when actually if you look at the bigger picture, it will cost us more because the patients will be more dehydrated and they'll be in hospital for longer with infections [...]" (HWS1, interview.)

Differing professional agendas were not only linked to 'buy in' or participation but also financial priorities and budgets. Once hospital-wide strategies were identified, implementation was through policy, projects, training and reviewed by audits:

“One of the big projects that I'm working on currently is a 'Mealtimes Matter' project, which has come out of a standard operating procedure [...] we've put together an audit tool [...] to make sure that the standard operating procedure is being adhered to.” (HWS1, interview.)

However, interpretation of policy may not be in keeping with the aims of the project:

“There are guidelines about [...nutrition and hydration], I'm not sure they entirely work in practice. [...] it's up to individual wards [...] they have

guidance such as protected mealtimes, so protected mealtimes are excellent in terms of giving someone the space to be able to eat. But unfortunately, sometimes these guidelines are taken out of context. And that means that instead of encouraging family and friends to come in and share a meal, the lights get turned off and no-one's allowed to come in.” (HWS3, interview.)

Opportunities for feedback from wards to the NHSG were limited to complaints or local surveys, often completed by relatives, which did not ask about hydration:

“There's always a patient feedback survey [...] at the end of their stay and one of the questions on that is ‘How was the quality of food during your stay at [hospital]?’ another one is: [...] ‘If you needed help at mealtimes did you get the help and support that you need?’ and they are fed back to the wards on a monthly basis.” (HW1, interview.)

The local survey questions captured data which aligned with the national priority and campaign, mealtimes. Therefore, when considering patient reported feedback, hydration may be lost as a priority compared to mealtimes. The NHSG was made up of professionals, with no relative and one patient representative; OPLWD and their relatives had very little influence on the NHSG priorities:

“We have a patient representative [...] who comes to the NHSG, they sit on the board and they can give their opinions [...] there isn't a carers' aspect to the board as far as I'm aware.” (HWS1, interview.)

Overall findings were that hydration care was given less priority compared to areas of care with national campaigns, direct financial implications or that were measured using specific, mandated metrics. Hydration lacked a whole-organisation approach, consequently the specific hydration needs of OPLWD had not been viewed from an organisational perspective. Where strategies were implemented, there was thought to be variation from ward to ward, however there were minimal channels for the organisation to monitor or gain feedback about hydration care delivery on the wards.

Nutrition and hydration were paired, with the emphasis on nutrition and mealtimes. The wards will be explored in the next section.

5.3 The wards: hydration is overshadowed at ward level and obscured from healthcare staff

This theme reports data which answers research question two using data from the observations, clinical documentation and interviews with ward staff. The subthemes demonstrate how hydration is overshadowed at a ward level, mirroring the organisational perspective. Pseudonyms have been used for the wards and names of any patients.

5.3.1 Other aspects of care are valued more than hydration: "*I am 1:1 ... because of the risk of pressure sores*"

The OPLWD participants had various acute and pre-existing physical health concerns on admission. Many staff-patient interactions related to care, however hydration, a physical care need, appeared to be less valued than other physical care needs. One reason may be that the priorities of the wards, particularly Elm and Fir, seemed closely related to harm-reduction and aligned with the organisational priorities monitored through quality metrics. Many substantive staff interviewed identified their ward area had specific priorities which may have been different to other ward areas. Specifically, on Birch there were references made to "acute-care" or that staff were skilled in multiple aspects of care due to the range of presentations and level of patients' acuity staff encountered. On Elm there was a focus on 'skin integrity' and a view that this was closely monitored by the WL. On Fir regular references were made to safe mobility, particularly falls prevention, which was seen as the main staff role when they provided 1:1 care for OPLWD. This finding at ward-level connects the organisational context discussed in section 5.2.1, demonstrating

how the link to national priorities which influence the hospital leadership, then influences the ward priorities and staff focus. These other areas of focus may be a reason that hydration is less discernible as a priority of care for healthcare staff at ward-level.

Even when hydration was an identified issue for OPLWD it did not gain prominence by staff. Cara, Gail and Ivan were all admitted with poor intake. For Cara, neither member of staff interviewed discussed this, although the HCA stated she required help with eating. No staff discussed this for Gail, although the HCA again discussed food but not hydration:

“[She] Is independent at certain times even though she has dementia. She can feed herself so you let her, but you make sure you supervise.” (HCA, Gail, Elm, interview.)

Gail did not share the HCA’s view of her independence, saying she would prefer to be reminded to drink as she forgets. The registrar was the only staff member working with Ivan who specifically discussed him having low intake.

Interactions provided by HCAs with OPLWD often related to monitoring physical health, such as assessing vital signs or blood sugars. During interviews, HCAs described their role in relation to the physical health of a person, related to recorded areas of care but often not including hydration:

“I am 1:1 with Cara because of the risk of pressure sores, she needs two-hourly turns and help with feeding, when the food orders comes she needs help with eating. She also needs help to make the food order. It is also my duty to help observe the clinical care like the blood pressure, recording the BM sugars and generally making sure she’s comfortable in bed, as well as getting her out for muscle relaxation.” (HCA, Cara, Birch, interview.)

Once again, the HCA discusses intake related to food, as did other HCAs:

“OK, my role is [...] to provide personal hygiene, nutrition, whatever nursing assistant duties [...] to support the nurses, to look after the patient and make them well.” (HCA, Hana, Elm, interview.)

On Fir in addition to discussing their role caring for physical needs HCAs, who were completing a bank shift also demonstrated they were not always aware of the individual, specific aspects required by the OPLWD:

16.49: The HCA asks Kay if she is wearing a pad, Kay replies, “no, I don’t think so” The HCA asks, “what are you wearing?” Kay says, “I don’t know” and shows her. (Kay, Fir, Obs 3, fieldnotes.)

An HCA compared the adult ward to a paediatric ward and found it lacked easily accessible information about the person, even when related to physical healthcare:

“With every dementia patient's folder, there should be [...]a] bit that just tells you like key tips [...] so if they have like diabetes, which is what this patient has, then they'll go through the protocol like in simple form what you need to do and stuff like that, so you're well aware of what you need to do whereas here you [have] to go searching for that sort of thing.” (HCA, Kay, Fir, Obs 3, interview.)

Physical health assumptions may be made by HCAs which impact their care delivery:

“He had coffee [...] and when I was making him coffee, my other colleague was like, ‘coffee? he won't sleep’ (HCA, Bill, Birch, interview.)

There were observations that demonstrated some staff across all wards had a risk averse attitude to care. On all wards HCAs prevented OPLWD from mobilising, presumably hoping to minimise the risk of falling, although this was only given as a reason to the OPLWD on one of many occasions that were observed. These interactions demonstrated staff prioritised safety, which did not always align with the

OPLWD's priorities but reflected the organisational priorities discussed in section 5.2.1.

5.3.2 A physical barrier to hydration care for healthcare staff:

"Before ward sisters could get into their own kitchen"

As well as hydration being overshadowed due to other priorities for healthcare staff at ward level there was also a physical barrier to hydration care. The wards had 'drinks rounds' throughout the day, provided by hosts employed directly by a private company, who were contracted by the hospital. The drinks round was conducted from a trolley with drink-making facilities onboard. Food and drinks were stored in the kitchen, which was the sole domain of the hosts and was not accessible to NHS employed healthcare staff, this was a source of frustration for the WL on Elm:

"Now unfortunately, the trust have a lot to answer for because before, ward sisters could get into their own kitchen [...] they could make a nice hot chocolate [...], put loads of milk in for the calories you can't do that anymore because of health and safety, it's wrong on so many levels [...] I used to be able to go, [...] at like 2 o'clock in the morning and if people used to wake up, you'll go: 'Do you need a [hot] chocolate?' [...] but it's just all gone by the wayside because of all the issues and it's a private firm [...] and it's wrong on so many levels because it just makes our job harder." (WL, Elm, interview.)

On the wards there was a designated beverage area where, theoretically, drinks could be accessed by patients and staff in-between drinks rounds. All wards had a different system for this; on Birch the beverage area was locked and only accessible by staff, on Elm it was open and accessible by anyone and on Fir the area was open but the drinks were only available through tokens stored in the WL's office. Staffing was a key aspect of the ward make-up and will be discussed in the following section.

5.3.3 Hydration is routinised to an outsourced worker, it is not part of the healthcare staff's routine: "*When the tea comes you can have one*"

The observational data demonstrated across the wards drinks were offered as part of a fixed routine by the host. The hosts did not divert from the routine, even when requested to:

13.39: The HCA brings a blanket and puts it behind Mae's back, she asks: "Do you want some tea?" Mae: "Jamie?" The HCA says she will come back later. She leaves the bay

13.40: The host arrives in the bay and says, "tea, coffee?" and leaves, the HCA asks the host to ask Mae again on her way back as she might want one then.

[Once the host leaves the bay they do not return. About 15 minutes later the HCA offers Mae some water, which she refuses; Mae does not get offered another hot drink but requests one herself over an hour later]

15.04: Mae to the HCA: "I need a cup of tea now" HCA: "OK I'll go and get you one" and leaves to get one. (Mae, Fir, Obs3, fieldnotes.)

This was one of the only occasions I observed an OPLWD requesting a drink without being offered one. The drink routine often did not benefit the OPLWD as they could not always get a drink outside of these times:

Visitor asks if there is any tea. HCA replies, "later." Visitor to June: "When the tea comes, you can have one." HCA tells visitor: "We made her some today and she didn't drink it." HCA is sitting near the bed writing in the notes. (June, Fir, Obs1, fieldnotes.)

An HCA perceived Elm to be more routinised than Birch, and therefore preferred working on Birch where he felt less constrained by routinised care:

“That's why I don't like going to Elm [...] because the nurses are not listening [...] they are more worried [...] what the matron [...] or what the day staff are going to say if you don't wash the patient [...] fine when there's bowel movements, or when they're wet [...] but when the patient is sleeping [...], you should let them have a proper sleep rather than forcefully waking them up to have a wash because you want to prove to your other colleagues that you have done something, at the expense of the patients, [...who are] being deprived of a rest by those who are meant to look after you,. I don't think that's ideal.” (HCA, Bill, Birch, interview.)

Due to ward routines, balancing OPLWD getting their fundamental needs met and promoting their own choice was sometimes difficult:

“He was sleeping when I came on shift and breakfast had already gone [...] I just opted to get [...] porridge[...] but I [didn't] want to wake him up, [but...] when he wakes up the porridge [will be] cold so I opted for cereal [...] when he woke up [...] I [asked him] would you like this or do you prefer something else, [...] And he was like, 'porridge will do' so [...] I went to scout for porridge, and unfortunately the last porridge was given, [...] so I came back and I told him, 'I'm sorry there's none left, but we've got this, can we still make do with this?' and he said 'yes.’ (HCA, Bill, Birch, Interview.)

This demonstrates that there are limits to providing choices outside the routines on the wards.

5.3.4 Views on dehydration: “Dehydration is not good”

When asked about hydration care, many nurses discussed hydration as it relates to the risk of dehydration:

“If we need to encourage the patients and monitor [...] their hydration and food we would do it. Uh, for instance, there's a patient here that really needs encouragement with their fluid intake [...] we're monitoring it, if they are dehydrated it can cause a lot of complications.” (Nurse, Ivan, Elm, interview.)

One nurse demonstrated they considered this when offering Bill a drink with his medications:

“He had a healthcare assistant that had been with him and his family were with him for a lot of the day and they're very good at encouraging him to drink [...] there was nothing clinical to suggest that he was dehydrated. But I just wanted to keep having that conversation with him to remind him how important it is.” (Nurse, Bill, Birch, interview.)

The second nurse was quite vague about dehydration:

“[...] If there's any skin damage or anything so nutrition and hydration is very important to healing and you know, dehydration is not good as well, for all of us.” (Nurse, Cara, Birch, interview.)

The risk focus of dehydration presents a harm-reducing perspective of care rather than a health-promoting or wellbeing one, and is reflected in the view of preventing skin damage. This view about preventing skin damage appears to come from a harm-reducing perspective rather than a health-promoting or wellbeing one. Only one HCA discussed dehydration and this was related to harm-reduction:

“I always [...] encourage her to drink because it's very good for them to avoid dehydration [...] I think drinking is the important things, because if they are dehydrated the more they will be you know like, agitated like that.” (HCA1, June, Fir, Interview.)

One of the most urgent and clear instructions heard about increasing oral intake was in response to a potential health concern:

18.41: HCA tells the nurse that Kay has not urinated all day, Nurse replies: “oh no” and asks the HCAs: “can any of you do a bladder scan?” They both say no. The nurse asks the HCAs to encourage her to drink lots of water, “a full jug” The HCA then says Kay had been to the toilet with the physiotherapist today but she is not sure if she passed urine. The nurse replies: “oh dear” and that Kay needs to drink lots, “we need to try and get her to pass before

we go off shift and we can do a bladder scan” The conversation is in Kay’s bed area but it is mostly amongst staff although Kay is listening. (Kay, Fir, Obs 3, fieldnotes.)

One minute later Kay asks to use the toilet and passes urine.

An OT and physiotherapist discussed dehydration in relation to how it related to their professional roles, discussed further in section 5.4.3.5. The physiotherapist also discussed how dehydration leads to other negative physical health changes, such as changes to blood. Elm doctors also identified negative impacts of dehydration and explained their role to assess if a person is dehydrated and treat or prevent delirium:

The consultant explained that they are lucky on [Elm] as the nurses keep accurate records or are in the ward round with them so they can ask them directly what the person’s intake is. They also explained that they use clinical assessments such as checking a person’s skin to see if they’re dehydrated. They also explained that part of their role is to break the link between low fluid intake and delirium, through fluid intake and that this can be preventative as well as in response to a delirium. (Consultant, Gail, Elm, notes from an interview.)

The registrar interviewed went into more detail regarding the clinical assessments for dehydration and specific complications they may be concerned about:

“So, there’ll be a range of assessments. [...] the collateral history, whatever the patient’s able to tell you [...] what they’ve been drinking, if a family have got concerns that they think there’s been a change in oral intake and then obviously looking at things like fluid balance charts, food diary charts and then moving on to our clinical assessment. [...] That’s looking at markers of hydration status, such as has someone got dry mucous membranes [...] presence of tachycardia, hypotension and then looking at their blood results. So, are they biochemically dehydrated? [...]and] putting all of that information together.” (Registrar, Elm, Birch, interview.)

The Elm doctors were the only healthcare staff who spoke about identifying, preventing and treating delirium. The nurses on Birch and Elm used the word 'delirium' or 'delirious' in their interviews, no nurses on Fir did. When these nurses talked about delirium the language used described the patient or complexities added to providing care, not something to be prevented or treated:

"She was quite delirious when she came in, so she didn't drink a lot for us at all." (Nurse, Daisy, Birch, interview.)

I heard two phlebotomists discussing how they too are affected by a person's low fluid intake:

Phlebotomist-to-phlebotomist: *"it's because they don't drink enough, it's hard"*
I ask the phlebotomist to explain more, they reply: *"if they drink more, their veins raise but mostly they don't drink"* she looks around the bay of older adults and says: *"it's good for us but it's also good for them if they drink [...] they don't because they don't want to go to the toilet, they're all mostly like that."*
(Phlebotomist, Cara, Birch, Obs1, fieldnotes.)

Most relatives interviewed thought their relative did not drink sufficient fluids and had an understanding about the importance of hydration, or related health impacts, usually through lived experience:

"I know that Daisy has had times in the past when she's had a lot of pain because of urine infection [...] one of the things she's sort of not that keen on drinking because the more she drinks the more she pees, [...] so I think that, and previous to that, urinary problems sort of made her think twice about drinking water." (Relative, Daisy, Birch, interview.)

Cara's relative also felt continence was a factor in Cara's reduced intake:

"The dietician says she needs to be drinking two litres a day. So, we're off that target [...] it's just a fight, [...] a real struggle to get her to drink [...] one of her reasons is: 'oh, it's going to make me pee all day.' [...] I say] 'but it doesn't

matter you're wearing a pad' [...Cara:] 'Oh, yes, but I'm still going to pee all day' (Relative, Cara, Birch, interview.)

Mae's relative felt adequate hydration improved her physical health and cognition:

Mae's relative explained that she's noticed there can be issues with getting Mae to drink enough fluids. When Mae drinks, she notices an improvement in Mae's cognition and she seems brighter. She felt that fluids may even be of more benefit than the medications Mae receives as even if she only has 300ml intake she can see a positive change in her. Mae's relative stated when Mae has a UTI the more water she can get down her the quicker they resolve and she notices her cognition and symptoms improve. (Relative Mae, Fir, notes from a telephone interview.)

The incongruence within the wards was that although there is a staff focus on tasks connected to physical healthcare, hydration, a fundamental aspect of healthcare was overlooked compared to other priorities and connected to the organisational priorities discussed in section 5.2. This was reinforced by physical barriers to healthcare staff providing hydration, through inaccessible kitchens and the routinised drink rounds being carried out by an outsourced staff member. Harm reduction was prioritised, especially when linked to monitored areas, such as skin integrity. Although hydration could have a role in reducing harm, it was scarcely linked directly with associated aspects such as skin integrity. Dehydration and delirium was considered a risk for OPLWD by some healthcare staff but was often viewed through the impact it would have on the staff members role or workload, rather than the OPLWD. Hydration was rarely linked to wellbeing by healthcare staff; relatives were more likely to view hydration through a link to wellbeing.

5.4 Whose role is hydration care?

This theme discusses the view expressed by staff that hydration care is ‘everyone’s role’ which contrasted with the observation that roles were compartmentalised and disjointed amongst ward staff.

5.4.1 Is hydration care everyone’s role or no one’s role?

“Anybody going past can offer a drink”

It emerged that a holistic, whole-ward approach to hydration was lacking, reflecting the finding in section 5.2, that a whole-organisation approach to hydration was lacking. Contrastingly, there was less awareness by ward-level staff that they were lacking a whole-ward approach, compared to the awareness among hospital-wide staff discussing the organisational approach. Many ward staff expressed a view that hydration was ‘everyone’s role’ however, in observable practice staff had divergent hydration roles. The individual roles were compartmentalised and disjointed which often left a gap in effective hydration care; sometimes hydration care was not delivered at all and when it was, it was mostly not person-centred.

Nurses and HCAs on all wards expressed that hydration care was part of everyone’s role:

“Anybody going past can offer a drink, it’s not a nursing job, and trying to get that mindset, is important, it’s everybody’s job.” (WL, Elm, interview.)

Other healthcare staff also viewed the role as belonging to everyone with stipulated caveats:

“I see it as everyone’s role to encourage fluid [...] but in regard to like monitoring the output and input, not specifically my role.” (Physiotherapist, Gail, Elm, interview.)

Although there was a widespread view that hydration care was everyone’s role, the

roles involved in providing hydration care were observably unconnected. This compartmentalisation of roles may explain the contradiction that although staff stated hydration was everyone's role, it was not clear who had overall responsibility. Subsequently, there was a question unanswered which was: whose role is hydration care?

5.4.2 Training, knowledge, and staffing: *"There's a variety of experience and knowledge throughout the MDT"*

Alongside various staff roles on the ward there were varying levels of formal knowledge and training about dementia and hydration care. Nurses noted the difference between a registered nurse and HCA's knowledge about the importance of hydration and perceived this could have a negative impact on the support OPLWD with hydration care. However, this did not lead to the nurses explicitly linking this to training that should be provided:

"This isn't like against HCAs, but I think sometimes if HCAs were maybe more aware of the importance of hydration that might encourage them to kind of work alongside us a little bit more in sort of helping patients with their drinking." (Staff Nurse, Bill, Birch, interview.)

Training specifically about hydration was rarely discussed though. One nurse did speak of the challenges to support OPLWD; when I asked what would help, she responded:

"I think we should have like easy trainings for all people saying how hydration is important as well. Something like from the very bottom to the very top because I think with the challenges [we are] forgetting about their basic things." (Staff Nurse Cara, Birch, interview.)

The idea that hydration is "basic" could be a reason for staff not discussing training about hydration training, as even this nurse, who had identified staff knowledge and

skills as impacting on hydration care and causing challenges implied it is a “basic” topic. Additionally, none of the wards had specific hydration protocols and, as identified in section 5.2.1, there was not a hospital-wide hydration strategy. The scarcity of formal information available regarding hydration protocols locally was noted by an occupational therapist (OT), this is discussed in section 5.4.3.5. In contrast to the idea that hydration care was basic, the Elm doctors described understanding hydration as an important clinical skill, discussed in section 5.4.3.4.

The Elm registrar discussed the differences in knowledge oral intake and how this could impact the relatives as well as OPLWD:

“I think there's a variety of sort of experience and knowledge base throughout a multidisciplinary team, [...] we've got really specialist nurses [...] who are really, really confident about dealing with these sorts of issues. But equally, there's still quite a lot of agency staff or student nurses who might have very little or no experience in these sorts of things. So, I think definitely as a team presenting a united front when we have discussions with patients and families is really important and to sort of manage expectations and not to give conflicting bits of information.” (Registrar, Elm, interview.)

Dementia training was seen by staff or all grades, across the three wards, as a requirement to provide successful care to OPLWD. The WLs on Birch and Elm both expressed a commitment to staff receiving dementia training. Fir was an outlier, as the WL interviewed had not had the training and staff shortages on the ward led to staff having their training cancelled:

“I think the problem is, is because the ward is so short-staffed, if you do have training that's booked, usually either it gets cancelled or we can't go because we're needed on the ward.” (Nurse, Mae, Fi, interview.)

This nurse expressed how she felt the cancelled dementia training, would have been valuable to conducting her role and she felt disadvantaged by the absence of it:

“You're kind of fumbling your way around in the dark it's like you don't know what the best thing to do is, like the whole day today I just thought, ‘I don't know what the best thing to do is,’ like how to manage the situation.”

(Nurse, Mae, Fir, interview.)

Hydration was not a topic covered by the hospital dementia training:

“The aims and objectives of the course are to improve people's confidence in supporting someone who is distressed [...] So, some of the niceties around that, interestingly, things like nutrition and hydration aren't actually on it, there isn't an hour nutrition and hydration- there was when it was a three-day course but there isn't now. That influence is done more at the bedside, I guess, and it will drip in.” (HW2, interview.)

The WLs, HW2 and OAT nurse explained alongside formal, classroom training, skills could also be developed through role-modelling but opportunities for role-modelling differed across the wards. On Birch, the WL and the OAT nurse both reported the OAT was very involved in day-to-day care of OPLWD. The Elm WL said she or a clinical practice facilitator provided most bedside training. On Fir the staff reported the OAT were someone they could ‘refer’ patients to, rather than someone to work alongside and learn from. I did not observe any learning through role-modelling. Fir was the only ward I observed the OAT nurse with an OPLWD. The OAT nurse attended as the OPLWD was distressed, however when the OAT nurse arrived, the 1:1 who been with the OPLWD left, so any learning opportunity was missed.

Training and formal knowledge related to dementia or hydration care varied among the healthcare staff, the hosts varied again in their knowledge and skills. Although the hosts were the main ward staff who offered and delivered drinks, according to

the hosts there was no expectation for them to receive any healthcare or dementia training. The OAT identified that dementia training would be beneficial for the hosts and organised this, however it was not included in the catering contract or deemed essential training. Regardless, the OAT organised and conducted dementia training, delivered during the hosts' lunch break, consequently hosts could choose to opt-out of attending. The two hosts interviewed had differing opinions on dementia training. One host, when reporting they had not had dementia training and did not think there was any need echoed the idea that providing hydration was a basic task, implied in the use of the word 'just':

"It's just giving drinks, so it's OK." (Host, Lily, Fir, interview.)

In contrast, the host who had received dementia training felt it had been helpful, saying in their seven-to-eight months in the role it was the only healthcare-related training they had received. The OAT nurse who provided the host's training explained the challenges in ensuring the hosts have the skills needed to work with OPLWD:

"So, we're getting them [hosts] tomorrow and next week, [...] we only get half an hour and their turnover is massive [...] A lot of them, this is their first job in this country, and English is probably their second language, [...] those are the barriers." (OAT nurse, Birch, interview.)

5.4.2.1 Staffing: "We use a lot of bank and agency staff"

In addition to various levels of formal knowledge and training amongst the ward staff, there were other staffing issues affecting care and a variety of employment contracts. Staffing issues were discussed by all WLs as affecting the ability to deliver care to OPLWD. The WLs from Birch and Elm both felt that issues such as

recruitment and retention set the scene for acute hospital care and reflected the national context. One WL viewed recruitment and retention as “*a severe national issue*” (WL, Elm, interview.)

Across the wards there was acknowledgement that use of bank and agency staff was necessary. The WLs revealed that staff working with different contracts — substantive, bank or agency — may harm team cohesion or shared knowledge, which could affect the care OPLWD received. During my observations, many staff working directly with the OPLWD were bank or agency staff who had only met the OPLWD that day, and this impacted ability to get to know the person, which is discussed in section 6.3.2. WLs suggested there were issues related to agency staff’s attitude and commitment to the ward, with the Birch WL saying that having the same bank and agency staff working regularly mitigated this:

“We use a lot of bank and agency staff, particularly at night [...] we're lucky actually, in that most of ours come back [...] regularly. [...] So, we don't [...] get that feeling [...] they're not part of the team, so they don't really try as hard [...] they do genuinely care about Birch. [...] Obviously, there will be people, [...] particularly agency staff that come who don't have the same vision, but I think that's a sort of endemic problem everywhere in the NHS.”
(WL, Birch, interview.)

The Elm WL expressed negative views about the high use of bank and agency staff, stating:

“The nursing assistants, the majority of them, unfortunately, at this moment in time are bank.” (WL, Elm, interview.)

Later, there was an acknowledgement that the quality was variable:

“Unfortunately, bank nursing agency, you know some are very good, some aren't, that's all I'm going to say on that.” (WL, Elm, interview.)

This view on the variation in quality may be explained by an acknowledgement that bank and agency staff have not always undergone the same level of training about dementia as substantive staff:

“As much as some of our bank [...or] agency nurses are amazing [...] I know for a fact that my [substantive] nurses have been through their dementia, two-day Trust training which is essential for all our nurses, irrespective of grade [...]. So, I know for a fact, the bank nurse that I’m paying, probably more, than my substantive member of staff [...] is not as well-trained at dementia or therapeutic [engagement] or thinking outside the box to try and control delirium and try and encourage oral intake.” (WL, Elm, interview.)

This was confirmed in the interviews I completed with bank and agency HCAs, as many stated they had not had formal dementia training provided through their roles. Fir was an outlier, the WL did not highlight any disadvantages with the use of bank or agency staff. Fir was also an exception as it provided all OPLWD a “special”, also called a 1:1. When the 1:1s were interviewed, they stated they were mostly employed through the bank or an agency. Fir was the ward most likely to have fewer staff than planned during a shift (see figure 5.1). Fewer staff could be relevant to the Fir WL’s views about bank staff as they automatically linked this with increased staffing to provide 1:1 care and how this made care, including hydration, easier:

“Yes, but if the patient’s got like specials like one of the patients at the moment is easy because [they’ve got a] 1:1 so they can monitor the patient and monitor their intake and output but if we’re short then it’s quite difficult sometimes.” (WL, Fir, interview.)

Figure 5.1: Staffing numbers for each observation per ward

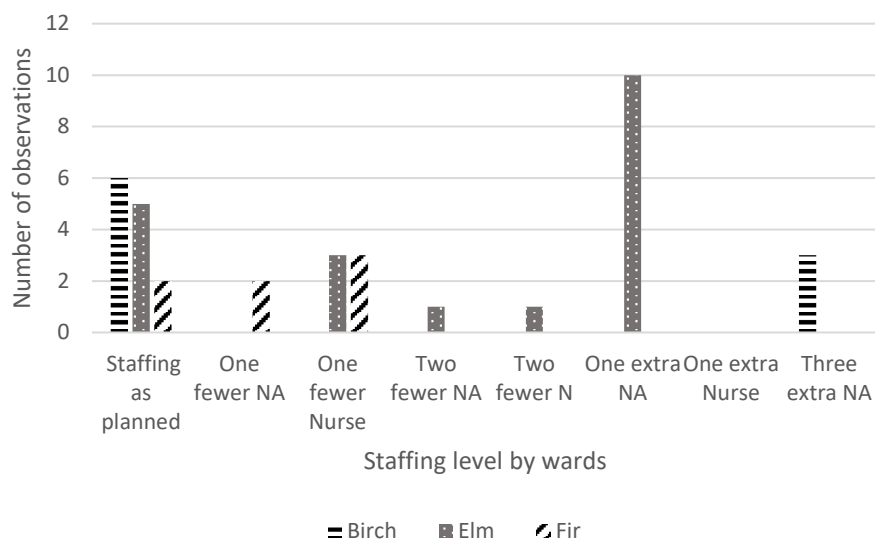


Figure 5.1 displays figures from boards displayed on the hospital ward that showed the staffing for the day. Figure 5.1 displays that on Fir the staffing was reduced more often than the staffing was as planned, and that there was an extra nursing assistant on Elm more often than the number recommended from the planned establishment, in keeping with what was identified by the WL. According to the Elm WL the planned staffing does not always produce the quantity of staff or skill mix that was necessary to fulfil the needs of the ward:

“We’ve been established for six nursing assistants across the board and across Elderly Medicine in general [...] However, the establishment is wrong because currently we are having to be topped up with bank, nursing agencies [...] due to the increase in dementia and very cognitively impaired patients coming through our doors. [...] This has been a huge increase in the workload [...] So, there is work going on at a strategic level to look at the [...] patient-to-nurse ratio” (WL, Elm, interview).

As differences were noted between substantive, bank and agency contracts and roles it is noteworthy that the hosts are employed by a private firm, on a different contract to the substantive ward staff.

In summary, substantive healthcare staff are eligible to receive dementia training provided by the hospital however this may not be possible due to chronic staff shortages on some wards. Dementia training does not include any training about hydration. The people providing care to OPLWD in hospitals are often bank or agency employed HCAs and they do not have to undertake any dementia training for their role. There is no formal hydration training, therefore hydration knowledge and skills are variable. The HCAs who provide direct care to OPLWD are likely to have less knowledge about hydration than qualified nurses. The medical doctors on the elderly medicine ward expressed that knowledge about hydration care was an important clinical skill and developed junior colleagues' understanding of this area. The hosts, who offer and provide most drinks to OPLWD on the ward, have the least training of all staff on the wards. They are not obliged to have had any healthcare training and dementia training is unofficial and optional. Furthermore, knowledge amongst the host team is challenging to sustain due to the high turnover of staff and there is a large amount of bank and agency staff providing care to OPLWD. The next section provides detail about the different hydration care roles.

5.4.3 The siloed nature of hydration care roles

This section presents a typology (see table 5.2), of the distinct staff roles for hydration care which were often unconnected. There is also a brief description of the roles of OPLWD and their relatives.

Table 5.2 A typology of ward staff roles and how they relate to hydration care for older people living with dementia

| Job role | Explanation |
|---|--|
| Hosts: “They don’t have any responsibility” | Task-orientated; to carry out drink rounds which were often completed with minimal interaction and minimal choice, in a reductive way. |
| Nurses: “I need to give you tablets” | Nurses acknowledged their duty and responsibility extended beyond other staff and that they had specific clinical knowledge about hydration. Most hydration care occurred during medication rounds, with medication as the primary aim and hydration a way to facilitate this. |
| Healthcare assistants: “The front line” | Healthcare assistants described their significance as they spent the most time with OPLWD. They gained knowledge about the OPLWD in the moment. They may prompt a person to drink what is within reach, more commonly at mealtimes but rarely source or deliver drink. They may not have had formal education about hydration. |
| Doctors: hidden role, minimise risk | Doctors described awareness of the acute risks of dehydration. Interaction with OPLWD was minimal. Occasionally, they documented about hydration in the multidisciplinary team (MDT) care records, this occurred more regular in the elderly medicine ward (Elm). |
| Physical and occupational therapists: guided by “The aim of the session” | Physical and occupational therapists were aware of complications associated with low fluid intake, but this did not often lead to direct care. They may have been unclear about how to record the intervention correctly, or feel their role was to advise nurses rather than directly provide care. Interaction with OPLWD was during the therapy intervention. Hydration was a mechanism to deliver or assess other aspects of care, not the primary goal. |
| Dieticians: “Refer to” | Nursing staff spoke about referring to dietitians if they identified concerns about malnutrition or low food or fluid intake. Dieticians documented in the MDT records. Documentation focussed on nutrition; hydration guidance was linked to food, i.e. “food and fluid intake.” Only one dietician entry provided a calculation of the oral fluid the OPLWD should receive. There were no observations with dieticians present. |
| Student nurses: front-line learning | Student nurses took a similar role to healthcare assistants, they sometimes prompted drinks which were already present, but did not deliver or offer other drinks. |
| Volunteers | The hospital leaders valued the role of volunteers to support hydration care. There was only one occasion where a volunteer was observed assisting an OPLWD, and this was during a mealtime. |
| Relatives | Relatives had knowledge about their relative’s hydration needs and preferences. Healthcare staff expected relatives to bring in an OPLWD’s preferences if they were unavailable on the ward, which they often did. Relatives did not always feel staff asked about or shared relevant information with them about their relative’s hydration. |
| Older people living with dementia | OPLWD had a passive role, hydration care was something done around them or to them, by others. An active role was not often encouraged or promoted. Although, if asked, most OPLWD could provide their preferences and hydration requests. |

Explanation of the typology is now expanded through related findings.

5.4.3.1 Hosts: "They don't have any responsibility"

The hosts, employed by the private external company to carry out the drinks round functioned in the same way across the three wards. The role was task-oriented, verbally offering hot drinks and then delivering the drink if one was accepted. This limited focus was acknowledged by some staff:

"They [hosts] don't have any responsibility [for hydration]. No, no, not at all."
(Nurse, Mae, Fir, interview).

Despite having no responsibility, the drink rounds were carried out independently, so hosts held a crucial role for the hydration care of OPLWD. Observations demonstrated that hosts completed a drink round in the shortest time possible, only offering tea or coffee; a choice of cup was offered on one occasion only. This reductive approach meant hosts did not complete all steps to make the drink ready for the OPLWD:

"When the caterers come around [...] if it's a tea or coffee round then they just put it all together [...] on the table, so they even leave a tea bag and spoon in the cup and sugar on the side [...] that's it." (OACNS, Birch, interview).

Hosts did not provide any care or interactions beyond what was required to offer a drink. There was no evidence of a mechanism in place that enabled hosts to share information with staff if an OPLWD asked them for something they could not provide:

8.25: Host attends and asks if he would like breakfast, Alan points to his feet (his socks are half on and only covering his toes). Host says, "the nurse is coming... cornflakes? Toast? Porridge?" Alan shrugs. Another staff member asks the host something and they walk away. (Alan, Birch, Obs1, fieldnotes.)

One host said they occasionally relied on healthcare staff telling them what the OPLWD likes to drink:

“They [OPLWD] normally respond when they’re asked, they mostly know what they want, or the nurses can tell [me].” (Host, Lily, Fir, interview.)

Hosts interacted most with the OPLWD during breakfast, as this interaction required a two-way dialogue about the OPLWD’s breakfast and hot drink choice and hosts immediately providing it. Drinks rounds were structured with the aim seemingly being to complete the routine, rather than offer each person a drink. The most common approach used by hosts was to walk into the bay and verbally offer “tea” or “coffee” without directing the offer at any specific patient. The OPLWD did not always notice the verbal drink offer, so missed out on this round. Drinks were also missed if the person was sleeping or away from their bed, such as when using the bathroom:

15.40: Caterer attends the ward to complete a drink round but as Gail is asleep, she does not get one. (Gail, Obs1, Elm, fieldnotes.)

Gail wakes up five minutes later

This was also one of several examples where it is unclear who noticed the OPLWD had missed a drink as there were no healthcare staff observing. If the OPLWD accepted or refused a drink during the drinks round, that information was not documented by the hosts. There were few occasions when a host made effort to communicate directly with the OPLWD beyond the minimalist, verbal approach, but this was the exception:

18.21: Host arrives and checks the bed board for instructions, asks: “You want tea?” Eddie responds: “Drink.” Caterer mimes drinking action and makes a ‘T’ shape with his hands. Eddie: “no.” Caterer holds up a teabag and

says: "It's good for you." Caterer tells HCA: "I'm going to make him one anyway, does he like tea or coffee? (Eddy, Elm, Obs2.)

Although the hosts have one of the key roles related to hydration - providing most offers and distribution of drinks, they do not have the majority of knowledge or understanding about hydration care for the OPLWD. A vacuity of communication and collaboration between the healthcare staff and hosts results in deficient hydration care.

5.4.3.2 Nurses: "I need to give you tablets"

Nurses across the three wards described sharing the hydration care role with other staff. They also acknowledged nurses had a duty and responsibility beyond other healthcare staff, particularly associated with fluid balance charts:

"[Nurses are] the ones that have that overall responsibility to make sure that they're hydrated [...] we've got to keep an eye on the fluid balance [...] we're the ones that have to like look at it and check that they're having enough."
(Nurse, Hana, Elm, interview.)

When discussing this, it was often described as an observational role:

"It should really be the staff nurse's role keeping an eye on somebody's fluid balance, what's coming in, what's going out, but I think everyone should be responsible for making sure people are getting enough to eat and drink."
(Nurse, Bill, Birch, interview.)

There was a view that nurses had greater knowledge than HCAs relating to the importance of hydration:

"I think [...] as a staff nurse there's maybe more understanding of the importance of hydration and sort of clinically how that can affect somebody." (Nurse, Bill, Birch, interview.)

Several nurses acknowledged that although hydration care had importance, documentation may not be highly prioritised:

“We just need to improve [...] recording intake and output at times we are very good and at times, due to staffing issues we tend to forget [...] sometimes we encourage the patients to drink or assist them to drink but [...] we forget to fill up the fluid chart which is not good because is not documented.” (WL, Fir, interview.)

Across the three wards, nurses predominantly participated in hydration care while carrying out other care; mostly through offering water while administering medication. During these times administering medication was the primary goal, offering a drink was secondary:

12.29: Nurse to June: “I need to give you tablets. Open your eyes.” Nurse attempts to give the tablets, saying: “swallow” and “water.” June asks for tea three times, saying: “I’d love a cup of tea.” Nurse: “OK, I’ll make you tea, have some water.” [...] HCA to nurse: “Did she have her tablets?” Nurse: “No, I’ll try with tea.” (June, Fir, Obs1, fieldnotes.)

Most interactions between nurses and OPLWD were related to medication administration, consequently the main time for nurses to facilitate hydration care was alongside medication administration. During interviews nurses did not often demonstrate they recognised this observation, they discussed being responsible for and promoting hydration as one of their duties, not specifically when linked to medication. Some nurses recognised that medication administration could promote hydration, however they may see this as additional hydration:

“So, with her I just offered a drink and she took it, [...] and she had that high protein milkshakes [...] as well. So, I’ve [...] given [it] to her hand and she drunk [it...] with the meds, I offered not like a single, [...] sip to swallow the medicine, but [...] I encouraged her to take another one. So, it’s always like extra, fluids coming in.” (Nurse, Daisy, Birch, interview.)

During multiple observation periods, medication administration was the only occasion an OPLWD was prompted to drink by a staff member. Although nurses did not often carry out hydration care outside of medication administration, nurses mostly documented daily information about the OPLWD's food and fluid intake in the MDT clinical records, although the wording was not very descriptive (discussed in section 6.1.2). Nurses reported healthcare assistants had the most time to carry out hydration care.

5.4.3.3 Healthcare assistants: "The front line"

HCA's recognised they had a key role, as they spent the most time with and provided most of the supportive care for OPLWD:

"As a nursing assistant you are the front line, especially monitoring fluids and the nurses are focussed on other tasks." (HCA, Gail, Elm, interview.)

Some HCA's reported their role was to use interactions with the OPLWD to assess what they could do themselves:

"At the start of the shift it might be a little bit different because hand over gives you an idea, but it doesn't give you [...] a full idea [...] So when you offer them a drink you see how they drink, how much they drink [...] that gives you an idea of how best to [...] encourage fluid intake. If you see that you give them a cup of tea and [...] you watch to see how they take that or [...] you can ask them [...] what do they prefer, tea, coffee, water? [...] and you see how well they [drink] (HCA 2, Hana, Elm, interview.)

HCA's also spoke of their role to prompt and encourage a person to drink:

"I've been like prompting him to [drink...] you just have to like try and remind them [...] just trying to encourage and [...] physically bring[ing] it down and talking them into giving it a go." (HCA, Bill, Birch, interview.)

Some also spoke of difficulties and emotional impacts when the OPLWD declined a drink:

“She refused to drink anything. She just refused any intake, no food, no drink, no water [...] it can be tiring and frustrating because this person wants to do one thing and you're trying to get them to do another.” (HCA, Mae, Fir, interview.)

HCAAs spoke of encouraging OPLWD, but observations demonstrated HCAAs mostly ensured the OPLWD was comfortable and encouraged them to drink at mealtimes:

12.44: HCA to Gail: “Gail, do you want lunch in your chair?” Gail: “No, it’ll be easier if I stay here.” HCA: “no problem” and changes Gail’s position [...] putting the table in front of Gail, ensuring that the tray is well positioned and opening the juice. (Gail, Elm, Obs1, fieldnotes.)

When HCAAs prompted the person to drink this was mostly with the drink that was within reach, usually water or a nutritional supplement, rather than offering a fresh drink, even if the OPLWD declined:

13.38 HCA to June: “Would you like a drink of milk [*nutritional supplement*]?” June: “No, I don’t like milk.” HCA: “OK.” (June, Fir, Obs1, fieldnotes)

Not offering new drinks could have been due to resource issues, discussed in section 6.3.4 but may also relate to perceived time pressures and other tasks being prioritised:

“There’s the beverage bay, but again, it’s sort of time, you know as soon as you make a cup of tea for someone you have to kind of do a round and there’s not really like the time for that.” (HCA, Hana, Elm, interview.)

As HCAAs do not often offer drinks to OPLWD beyond those already within reach, they may perceive it has the host’s role and not theirs.

HCAAs who prompted OPLWD to drink the most outside of mealtimes were on Fir ward where they were providing 1:1 care.

Although HCAAs viewed their role as key to hydration care, they may not have had the underpinning clinical knowledge about the importance of hydration care and possibly did not see sourcing drinks as part of their role.

5.4.3.4 Doctors: hidden role

Doctors were observed to interact with OPLWD most regularly on Elm, although there was no regular doctor-to-OPLWD interaction on any wards. The Elm doctors also documented about hydration care in the MDT clinical records more regularly than others.

Through doctors' entries in the clinical records, also discussed in section 6.1.2.1 their input into and views about hydration were partly considered. In Birch's clinical documentation, oral hydration was not often discussed often but intravenous fluids were documented. Doctors on Fir only documented about fluid intake at admission or discharge:

"Eating and drinking" [...] MFFD [medically fit for discharge] [...] Plan: Discharge planning." (Kay, Fir, MDT clinical records.)

Or, if there was a specific problem identified that hydration may be related to:

"BNO [bowels not opened]? Fluid in 840, 1340 out, 500 -ve. [...] Impression: 1) constipation...Plan: please continue FB and food chart" (Mae, Fir, MDT clinical records.)

The Elm doctors described their role identifying and educating junior doctors about low intake to prevent risks and liaising with patients and their families about hydration and the health impacts.

Doctors may have had hidden hydration roles, on occasion clinical decisions were seemingly made without the rationale being documented in the MDT records. During one observation a nurse began administering intravenous fluids to Cara, I asked the rationale but the nurse had not been told anything other than they had been prescribed. As there was no documented rationale the nurse recommended, that I ask the prescribing doctor who informed me the blood results indicated that Cara was at risk of an acute kidney injury, so they had prescribed intravenous fluids as a preventative measure. There was a risk related to this area of undocumented, hidden care, as shortly after Cara was transferred to another ward and it seemed this information could be lost.

5.4.3.5 *Physiotherapists and occupational therapists: guided by "The aim of the session"*

The physiotherapists and occupational therapists (therapists) had knowledge about the potential for OPLWD to have reduced hydration and related health consequences. They described having a responsibility to promote hydration. Observations demonstrated their role did not lead to many instances of overt direct hydration care. Their input with OPLWD was directly related to their therapy assessment and treatment, hydration was occasionally prompted when they closed their session:

10.44: The last thing the physiotherapist says to Gail is: "Make sure you're going to the toilet with nurses and keep up your fluids." (Gail, Elm, Obs2, fieldnotes.)

When asked why they encouraged Gail to 'keep up' fluids they responded:

Increasing your fluid intake will obviously lead to going to the toilet and [for] patients who are [...] are able to walk to the toilet, It's [...] good practice for them [...to], practise their transfers. [...] There was a patient who wasn't [...]

drinking enough water because they didn't want to get up and mobilise [...] So, it's sort of like a chain, they don't drink enough water because they don't want to mobilise, [...] you've got to be careful [...] because [...] then that leads to them becoming dehydrated and then changes in their blood pressure and then if they need to go to the toilet they will either hold it in, which will lead to a UTI.” (Physiotherapist, Gail, Elm, interview.)

The physiotherapist discusses how reduced intake can lead to other negative physical health changes. One potential reason that therapists do not provide direct hydration is because there are no clear guidelines:

“I'm not fully aware of the policies around how [...] hydration] should be recorded or if I should be handing anything over to the nursing staff, [...] it might be better to be more aware of the policies around that internally.” (OT, Birch, Daisy, interview.)

The nutrition and hydration policy did not include information about recording fluid intake. Alternatively, therapists may see their role as providing guidance to staff rather than direct care:

“If someone has [...] a] cognitive impairment [...] or needs to [be] prompted [...] I would normally just pass on to the nursing staff: ‘oh please, [they] either need a red tray or [...] prompting all the time’ or, ‘make sure [there’s] always a water on the table’.” (OT, Ivan, Elm, interview.)

The therapists also assess the OPLWD’s functioning for discharge planning, which was reflected in the MDT clinical records on Elm and Fir and therefore hydration is viewed for how it impacts discharge plans:

“It also helps me identify any needs in the community [...] when I'm looking at [...] their notes and understanding if they are dehydrated or having poor oral intake [...] then] I can make sure [...] their care package [is] adequate enough to be making sure they're regularly having that prompting for oral intake if needed or whether they potentially need an increase if they've come in with dehydration.” (OT, Daisy, Birch, interview.)

The therapists understand hydration care and how this influences other aspects OPLWD's care and functioning, however in their role, hydration becomes a mechanism for assessing and delivering other aspects of care rather than the primary goal.

5.4.3.6 Dieticians: "Refer to"

Dieticians were not present during any observations but held a role which was valued by nursing staff who discussed referrals to them as an available resource:

"We work with a dietitian just to enforce food and fluid to [...OPLWD]"
(Nurse, Ivan, Elm, interview.)

The nursing clinical records suggested nurses referred to dieticians based on the Malnutrition Universal Screening Took (MUST) score:

"MUST score- 2 "TREAT"- refer to dietician" (Lily, Fir, nursing records.)

Evidence of dietician involvement was visible in the MDT clinical records if they had assessed a patient:

"Referred for oral nutritional support [...] family are concerned re low intake over past few months, [...patient] did not want to discuss oral intake [...] Impression: Inadequate PO intake to meet requirements [...] Plan: 1) Commence Ensure plus 2) Please encourage intake little and often throughout the day. 4) Order fortified milk 5) Encourage food and fluid intake and document on food and fluid chart." (June, Elm, MDT clinical records.)

Only one dietician entry provided a specific fluid intake target for the OPLWD. One nurse felt it would be beneficial if dieticians had a more hands-on role:

"The dietician really is a part of it they could give the patient food preference that they want, if they could help, like for example feeding the patient or

bringing some food. [...] they could help us a lot.” (Nurse, Ivan, Elm, interview.)

There was a connection with OPLWD who had been referred to the dietician and having hand-written guidelines indicating their food preferences. Nurses valued dieticians support with promoting intake but based on dieticians’ documentation they mostly focussed on nutrition.

5.4.3.7 Student nurses: front-line learning

There were student nurses on both Elm and Fir. They reported similar views about their roles as HCAs and they conducted hydration care in a similar way, including offering the drinks within reach rather than offering fresh drinks:

*16.12: St/N says: “Hello” [...] Looks at the mug, asks: “Do you want this tea?”
Gail: “No, I’ve finished, it’s cold.” St/N: “Ah, OK, I’ll top up your water then.”
(Gail, Obs3, Elm, fieldnotes.)*

One interaction between a nurse and student nurse was observed which was illuminating, the nurse was explaining to the student nurse how to prompt and monitor hydration:

8.27: Nurse explains to the St/N that Gail can communicate and she should encourage Gail to drink, she also explains the jug and cup volumes and encourages the St/N to monitor and measure Gail’s intake. The nurse pours a cup of water and says to the St/N: “Then we leave it here.” Gail picks up the drink. (Gail, Obs2, Elm, fieldnotes.)

Several staff members described using the jug to monitor intake. However, this is unlikely to be accurate as OPLWD are also offered hot drinks and cups of water may be taken away by hosts without communicating or recording if the drink has been consumed.

5.4.3.8 Volunteers

Volunteers were portrayed by hospital-wide staff as being key to delivering hydration care:

“[...] We've also got volunteers [...] they go and buy drinks for patients or make drinks for patients or help patients drink so I think they're really key as well.” (HWS5, interview.)

However, from observations and interviews the role volunteers played was limited. A volunteer was observed to directly assist an OPLWD on only one occasion and this was during a mealtime:

12.26: Volunteer goes over to [...] assist with lunch. The volunteer is successfully assisting Eddy to eat [...] Volunteer says: “More water?” Eddy: “OK” and drinks with assistance. He has one sip and moves his hand in a no more gesture. Volunteer: “One more?” Eddy has one more sip and then gestures no more. Volunteer puts the cup down and leaves. (Eddy, Elm, Obs3, fieldnotes.)

There was one other occasion a volunteer was observed, but they did not interact directly:

11.15: A volunteer arrives in the bay to see if anyone would like assistance with shopping - no one does. (Hana, Elm, Obs1, fieldnotes.)

Hospital-wide staff felt volunteers had a key nutrition and hydration role but the observations indicated their role was not very widespread across the wards and ward-staff did not discuss their role.

5.4.3.9 Relatives

Across the wards relatives visited their family members regularly. They had knowledge about their relative's hydration preferences, most said hydration was an

area their relative required support or perceived that their relative had a lower than adequate intake:

“She’s probably not been drinking as much as she should [in hospital].”

(Relative, June, Fir, interview.)

They described their relative’s intake had decreased in hospital and had suggested strategies to improve this:

“She does need reminding to drink and so I make a big point of doing it with her [...] she’ll do it more if she sees it as a social thing [...] But the way she’s been so muddled, since she’s in here, I’m sure she wouldn’t be thinking about drinking unless someone’s telling her to do it.” (Relative, Gail, Elm, interview.)

Nurses and HCAs across the wards said if an OPLWD had a drink choice which was unavailable on the ward they would ask or expect the relative to bring this in:

“Families bring in things anyway, [...] if they enjoy a particular drink [...] then we encourage them to bring it in for them because obviously we’re not in a position to provide it [...] and [...] obviously, if they say to us [...] ‘Ethel loves [...] orange squash’ [...] then we try and make that happen” (WL, Birch, interview.)

Relatives that visited asked their relative about their food and fluid intake and often brought items with them:

14.35: Two visitors [...] arrive for Eddy. [...] One visitor had left and reappeared with lots of chocolate and drinks, including a carton of juice and a cup of water. [...] Eddy is sitting up [...] holding a cup of water that his relative gave to him. He is looking at them and taking independent sips. He looks relaxed. (Eddy, Elm, Obs3, fieldnotes.)

When relatives left additional drinks for the OPLWD, the staff did not always offer this to the OPLWD:

“Everyone keeps giving him water [...] and he keeps declining it, I thought OK, let's try something [different]. So, I just put the [flavoured] water in the cup and gave it to him with a straw and he drank it [...] His family bought the flavoured water, but it was just on top of the cupboard.” (StN Ivan, Elm, interview.)

Some staff felt relatives should do more to help care for the OPLWD:

“Family, [...], when they come into hospital some of them are still keen to help, but some of them, they won't do nothing [...] I think everyone should be involved [...], not just standing and waiting and they will say like, "oh, she's thirsty I think" but won't offer the drink you know.” (Nurse, Cara, Birch, interview.)

This nurse was observed to ask Cara's relatives to assist with hydration, but no other staff were observed to make direct requests to relatives. Relatives did not always feel staff had shared information about the OPLWD's hydration care, so were unsure if they should assist:

“I don't know that she has been drinking [...] because we'd like to support what they're doing here and if we know that she's not drinking very much, well when we're with her we'll keep jogging her a bit more than we might [...] I don't know how much she's drunk.” (Relative, Gail, Elm, interview.)

Staff reported that when relatives are present the OPLWD may drink more fluids independently, which matched observations:

“Everybody has tried to give her something to drink and she refused it [...] her [relative] came, she drank juice, she drank water, she had tea, [...] you [would] think that I wasn't trying at all, but I was and she was just refusing but now that she sees somebody that she's comfortable with [...] it helps” (HCA, Mae, Fir, interview.)

Not every OPLWD participant had a relative that visited but most did, when relatives visited the OPLWD seemed more relaxed and this led to them consuming fluids.

Relatives communicated an understanding that the OPLWD's functioning was reduced while in hospital and they had lower fluid intakes compared to pre-admission, or that fluid intake was an area they required support with before the admission too. Relatives asked the OPLWD about their intake when they visited and demonstrated wanting to assist, however they did not always have information about the hydration care plans. Relatives often communicated that hydration was linked to social activities which contrasted with the way staff discussed hydration.

5.4.3.10 Older people living with dementia

OPLWD were observed to have a passive role relating to hydration care, which was something that was done around them or to them. There were limited opportunities for OPLWD to take the lead in requesting a drink or making themselves a drink. The specific interactions, strategies and barriers to person-centred hydration care are explored through chapter six.

5.4.3.11 Summary of whose role is hydration care?

Healthcare staff in the distinct groups held similar roles to others within their group, regardless of which ward they were working on. The exception to this was with the doctors, as on Elm the doctors seemed to consider hydration more regularly as part of their ward rounds and were observed more often than on the other wards.

The compartmentalised roles held by staff affected the hydration care and were observed to result in a disjointed process with a lack of clarity over who was taking the lead in the process of hydration care for OPLWD.

5.5 Chapter summary

This chapter has described the hospital and ward contexts that oral hydration care for OPLWD takes place in. The acute hospital context is described through the

interviews conducted with hospital-wide leadership, which highlight there are minimal formal policies or strategies relating to this area of care. The findings demonstrate that the organisational priorities are driven by a national agenda, including areas of care that are measured, related to risk-reduction or have had a national campaign; hydration does not fit into their priority areas. This has resulted in hydration care within the hospital being obscured from the organisational agenda. As a result, the data about hydration reported up from wards to the organisational level is limited.

The chapter then explored the ward context, which reflects the organisational agenda. Healthcare staff prioritise areas of care based on a risk management approach or care which is reported and recorded, hydration care is not a priority in these ways of considering care. There is a further obscuring of hydration care from healthcare staff on the wards as the process of drinks delivery is facilitated by a private company, with staff who receive no healthcare training performing drinks rounds.

Finally, the roles related to hydration care are collated in a typology. The overall finding suggests that although staff may feel that hydration care is everyone's role the roles are mostly unconnected and compartmentalised which jeopardises the ability to deliver hydration care adequately for OPLWD in acute hospital wards.

6 Findings: strategies for, and barriers to, delivering person-centred hydration CARE

This chapter presents themes and subthemes of strategies for, and barriers to, delivering person-centred hydration care, to answer research question four, as presented in table 6.1.

Table 6.1 Research question four: themes and subthemes

| Question | Theme | Subtheme |
|---|------------------------------|---|
| 4. Using the concept of PCC how can hydration care for OPLWD in acute hospital wards be facilitated and what are the barriers? | Communication | Communication between staff and OPLWD |
| | | Communication between staff |
| | | Communication between staff and relatives |
| | Action | Providing direct support with hydration care for OPLWD |
| | | Leadership |
| | | Associated areas of care |
| | Resources | Identifying OPLWD |
| | | A documentation system to record information about the OPLWD |
| | | Identifying people who require additional help with eating and drinking |
| | | Choices and availability |
| | Environmental aspects | Social environment |
| | | Physical environment |

The themes, developed from data collected through direct observation, documentary analysis of clinical documentation or policy, and interviews with ward leaders, ward staff, older people living with dementia (OPLWD) and relatives are: Communication, Action, Resources, and the Environment, creating strategies which promote hydration (CARE). The themes are explored separately, in the order presented in table 6.1, with examples of the strategies and barriers in practice; however, the strategies complement each other in practice. Tables displaying the individual strategies and barriers within each theme can be found in appendices 32 - 35.

6.1 Communication

The hydration strategy most observed and reported by staff across all wards was communication; barriers to effective communication were also identified. Communication strategies and barriers related to three areas: communication between staff and OPLWD, communication between staff, and communication between staff and carers.

6.1.1 Communication between staff and OPLWD

Staff identified several verbal communication strategies for providing hydration care:

- Verbal encouragement: *“You can only encourage them and offer, keep offering and hopefully they will take it at some point.”* (HCA, Hana, Elm, interview.)
- Reminding the person to drink: *“To make sure that they are hydrated throughout the day [...] just to keep reminding them.”* (St/N, Lily, Fir, interview.)
- Prompting them: *“Just trying to encourage and prompt them and probably, physically bring it down and talking them into giving it a go”.* (HCA, Bill, Birch, interview.)

These strategies were not always observed in practice. Communication often happened alongside action strategies, which will be discussed separately. Verbal communication was most successful alongside non-verbal communication; a reliance on verbal communication alone could be a barrier to effective hydration care.

Successful hydration care for OPLWD was observed with the following communication techniques: allowing time, making eye contact, smiling, orientating them, speaking directly to them and getting to their eye level, often combined with action:

13.11: The nurse [...] lifts the juice off the table, looks at Daisy and says, “do you want the rest of your apple juice?” Daisy: “oh yes” the nurse [...], lifts it up and closer to Daisy. While Daisy is drinking it the nurse stays, Daisy asks the nurse, “what is it?” and the nurse reads the packet out loud, “premier apple juice from concentrate.” (Daisy, Birch, Obs3, fieldnotes.)

In this example, a combination of verbal and non-verbal communication techniques successfully promoted hydration. Sometimes verbal plans are given directly to the OPLWD:

“The doctor [...explains] to Gail that she has developed an irregular heart rhythm which is quite common when people are dehydrated. They [...] tell her to drink plenty of water and to get back to walking.” (Gail, Elm, Obs2, fieldnotes.)

However, it was unclear if any staff caring for Gail were aware of this care plan; certainly no healthcare staff encouraged Gail to have any oral fluids during the further two and three-quarter hours of this observation, although IV fluids were being administered throughout. Communication between staff is discussed in section 6.1.2.

Another nurse described the way they facilitated care to Eddy, despite communication barriers:

“Because he doesn't speak any English [...] I try to communicate through signs and pointing, showing things and going for a walk, [...] if he gets too stressed about something that I cannot understand or he cannot pass the message on, I just take him for a little walk, everything becomes easier and he relaxes a lot and then I can give the treatment that he is awaiting.” (Nurse, Eddy, Elm, interview.)

The nurse expanded, describing how they perceived their communication differed from staff who had difficulty engaging Eddy to provide hydration or other care:

“The HCA, [they] just come and do [their] job, I'm not saying that's wrong, [they're] doing [their] job. But sometimes [they] can come across as a bit [...] in [your] face, too straightforward [...] and Eddy, every time he sees [them], he connects [them] to something that's not very good for him, and he refuses [...]the HCA] can't get anything from [Eddy]. And when I come to him, [...] I think [...] he notices the tone of your voice being a bit more friendly, kind, [...]. I get anything [...] because I just drop to his eye level and I speak very slowly and I have all the patience, to wait for him, to listen to him, give time for him. [...] the night nurse said: "I couldn't give [Eddy] the medication [...] he's refusing everything [...] he's too distressed [...]I said:] "Leave [it] to me." I got the medication, when I see him [Eddy], he just looked at me, he smiled and he wave[d] at me, I go to him: "Eddy, now it's time for your medication, can you take this for me please? And then after that [...] "I can give you a cup of tea, [...] Yes, can you take for me please." He took [them] all. [...] it's the time and the tone of voice, and just like speaking to the eye level [...] If you talk over him, they get scared” (Nurse, Eddy, Elm, interview.)

In this description, providing time to the OPLWD was required for successful hydration care, however, most interactions observed across all wards were short in length, as shown in table 6.2.

Table 6.2: Length of interactions by ward

| | | | Ward Name | | | Total |
|--------------------|------------------------|-----------|-----------|----------|----------|----------|
| | | | Birch | Elm | Fir | |
| Interaction Length | 2 minutes or less | N | 143 | 204 | 213 | 560 |
| | | Ward (%) | 79.4 (%) | 81.6 (%) | 70.8 (%) | 76.6 (%) |
| | | Total (%) | 19.6 (%) | 27.9 (%) | 29.1 (%) | 76.6 (%) |
| | 3 minutes - 10 minutes | N | 28 | 41 | 75 | 144 |
| | | Ward (%) | 15.6 (%) | 16.4 (%) | 24.9 (%) | 19.7 (%) |
| | | Total (%) | 3.8 (%) | 5.6 (%) | 10.3 (%) | 19.7 (%) |
| | 10 minutes or more | Count | 9 | 5 | 13 | 27 |
| | | Ward (%) | 5.0 (%) | 2.0 (%) | 4.3 (%) | 3.7 (%) |
| | | Total (%) | 1.2 (%) | 0.7 (%) | 1.8 (%) | 3.7 (%) |
| Total | | N | 180 | 250 | 301 | 731 |
| | | | | | | |
| | | % | 24.6 % | 34.2% | 41.2% | 100.0% |

Most interactions, with any staff group, lasted two minutes or less; across all wards, 76.6% of the interactions fit into this category. Short, task-focused communication was not always successful to meet the needs of the OPLWD, particularly as OPLWD often had impairments which impacted on communication. Impairments were caused by one or several reasons, such as: hearing, sight, confusion, pain, discomfort, anxiety, tiredness, or English as a second language. The majority of short, verbal communication that ignored non-verbal communication presented a barrier to communication strategies.

Across the wards hosts always provided interactions of 2-minutes or less, offering drinks using the minimum verbal communication required; once the drink was delivered the host left immediately. Often, the host did not acknowledge the OPLWD directly, they walked into the bay of beds and said the words “tea, coffee” to the bay. On several occasions, this did not result in any response from an OPLWD. Healthcare staff expressed frustration about this:

“With the kitchen people, [...] if someone's asleep or not answering they just like, go away they don't try to wake up or encourage [them], like, " Would you like something?" [...] they just leave the patient without anything. [...] there was another [patient] she has [...] problems with her hearing [...] there was a [host] just like shouting, "tea, coffee" and [they] just went away because there was no answer. So, when I went closer to that [patient] and I said, "would you like tea or coffee?" like louder, [they] said, "oh yeah! cup of tea, please" [...] some people [...] they're rushing within [...] their usual daily routine and they just don't bother.” (Nurse, Cara, Birch, interview.)

There was one occasion observed when visual prompts were used by the host; the host made a 'T' shape with their hands, presented in 5.4.1. On one occasion a host disregarded Finn, speaking directly to the HCA:

“8.48: The host enters the bay, saying to the HCA: "what about him?" [gesturing towards Finn]. The HCA [replies...]: "you can ask him, he will tell you" (Finn, Elm, Obs1, fieldnotes.)

Gail's relative also highlighted communication difficulties:

“You're probably aware that the man turned up with tea [...] The only thing with [Gail], if she hears an accent, she often doesn't give herself a chance to understand what they're asking her, she always says, "I can't understand what they've asked me" and it's partly the hearing and it's partly an unfamiliar accent that she doesn't try hard enough to understand.” (Relative, Gail, Elm, interview.)

Of relevance may be that hosts had the least healthcare or dementia training, as discussed in 5.4.2, so perhaps did not always feel confident communicating with OPLWD. Additionally, unlike meal choices, there was no menu to facilitate beverage choice, perhaps as meals were more valued (discussed in section 5.2.1). However, hosts were not unique in favouring verbal communication; across the wards most interactions between staff and OPLWD were verbal, short and focussed on a specific task.

Healthcare staff often delivered hydration communication while other non-hydration care activities were being completed or during mealtimes, rather than stand-alone interactions:

17.54: HCA says to June: “let’s have some dinner.” June says she’s already had dinner and points at food saying she doesn’t eat that [...]. The HCA offers June a cup of tea, June declines and says she’ll have some in 10 minutes. (June, Fir, Obs3, fieldnotes.)

June continued to refuse eating the meal and was not offered another drink for over an hour when her relative arrived and offered her a hot drink.

This could be explained by other care areas being prioritised over hydration care, as discussed in 5.3.1; table 6.3 shows that 70% of all interactions across the wards were not related to hydration. Even in Fir, where the OPLWD had the most interactions, due to always having a 1:1 staff member with them, over 70% of interactions are not related to hydration. This includes Fir where OPLWD had the most interactions, due to always having a 1:1 staff member with them. The times when a drink was offered and accepted, this was mostly facilitated by hosts.

Table 6.3: Hydration interactions by ward

| | | | Ward | | | Total |
|-----------------------|---|---------------|--------|--------|--------|--------|
| | | | Birch | Elm | Fir | |
| Hydration interaction | Independent fluid intake | N | 3 | 3 | 7 | 13 |
| | | % within Ward | 1.7% | 1.2% | 2.3% | 1.8% |
| | Oral fluid intake with assistance | N | 9 | 9 | 0 | 18 |
| | | % within Ward | 5.0% | 3.6% | 0.0% | 2.5% |
| | IV fluid | N | 5 | 1 | 0 | 6 |
| | | % within Ward | 2.8% | 0.4% | 0.0% | 0.8% |
| | Missed fluid opportunity | N | 4 | 3 | 2 | 9 |
| | | % within Ward | 2.2% | 1.2% | 0.7% | 1.2% |
| | No fluid intervention delivered or received | N | 114 | 172 | 226 | 512 |
| | | % within Ward | 63.3% | 68.8% | 75.1% | 70.0% |
| | Offered and refused | N | 8 | 13 | 21 | 42 |
| | | % within Ward | 4.4% | 5.2% | 7.0% | 5.7% |
| | Offered and accepted | N | 21 | 22 | 15 | 58 |
| | | % within Ward | 11.7% | 8.8% | 5.0% | 7.9% |
| | Oral fluid with medication | N | 7 | 8 | 7 | 22 |
| | | % within Ward | 3.9% | 3.2% | 2.3% | 3.0% |
| | Fluid requested by patient | N | 0 | 2 | 1 | 3 |
| | | % within Ward | 0.0% | 0.8% | 0.3% | 0.4% |
| | Other hydration related interaction | N | 9 | 17 | 22 | 48 |
| | | % within Ward | 5.0% | 6.8% | 7.3% | 6.6% |
| Total | | | 180 | 250 | 301 | 731 |
| | | % within Ward | 100.0% | 100.0% | 100.0% | 100.0% |

Communication strategies between staff are discussed next.

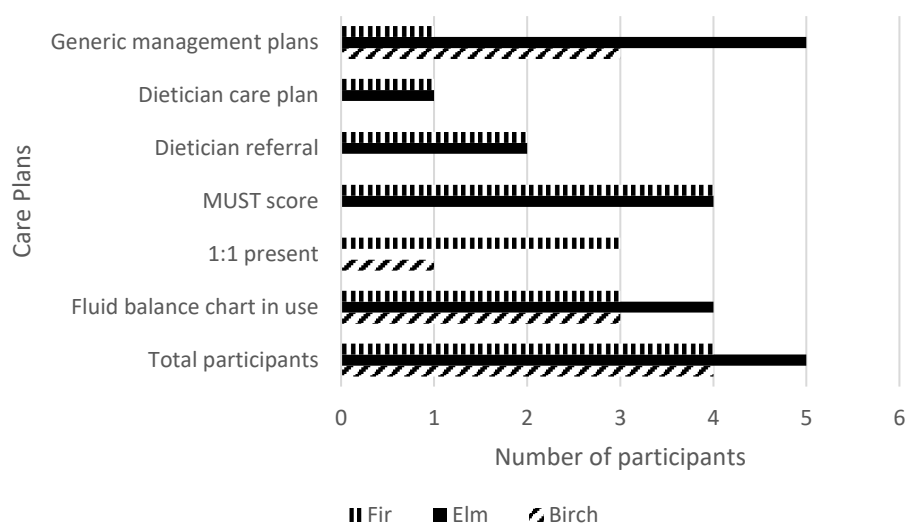
6.1.2 Communication between staff

To provide hydration care, staff need to communicate with each other verbally or through written clinical documents. All participants had two formal clinical records in paper files: multidisciplinary team (MDT) clinical records, and nursing clinical records. There was a recognition on Elm that documentation provided a way for the MDT to communicate about hydration:

“The first thing my consultant will look at when [...] doing [their] ward round [is the fluid balance chart] and [they] want to see what total did they have [...] yesterday” (WL, Elm, interview.)

However, medical staff did not regularly document about hydration (discussed in 5.4.3.4). There was also a combination of hospital-created generic management plans and staff created assessments, care plans and handwritten records within the clinical records. Generic management plans were kept in the nursing clinical records and included areas such as dementia, urinary tract infections, risk of falls, delirium, risk of absconding. However, there was no generic plan for hydration care or fluid intake. Figure 6.1 shows the relevant plans in place by ward.

Figure 6.1 Care plans or strategies in place by ward for the older people living with dementia participants



Malnutrition Universal Screening Tool [MUST] scores determined whether a patient required a dietician referral. Most Elm and Fir participants had MUST scores calculated; Elm and Fir were the wards where participants had dietician referrals. One participant on Elm and one on Fir had a dietician care plan; one of these included a target fluid intake, calculated as 1530ml. The dieticians' care plans included strategies to increase intake, but were situated within lengthy MDT clinical records, which were not easily accessible to all staff, particularly HCAs who mostly used the nursing records but interacted with OPLWD most (see section 5.4.3.3).

All Elm and most Birch participants had generic management plans but no staff discussed them during interviews. There was variability amongst other care plans across the wards and between the participants.

Fluid balance charts were used on all wards. There was one participant per ward (Alan, Finn, and Lily) who had inactive fluid balance charts, with no documented rationale for discontinuation. The recorded intakes of these participants on the day

of discontinuation were: 400ml, 990ml, 750ml; considering the only visible dietician calculated target was 1530ml, these intakes could all be considered low. Additionally, after Lily's fluid chart was discontinued, she had a MUST score which prompted a new referral to the dietician, but the fluid chart was not recommenced. Table 6.4 shows that even when fluid charts were used, they were not used consistently, accurately or regularly reviewed.

Table 6.4: Table of fluid chart information

| Participant Name | Chart in place at time of observations ? | Number of days chart totalled* | Mean fluid intake (ml) | Number of days that the fluids offered but not consumed were recorded* | Types of fluids recorded | Any other comments |
|---|--|--------------------------------|------------------------|--|---|--|
| *The 'number of days' refers to the total number of days a fluid chart was found to be in use | | | | | | |
| Alan | No | 1 out of 4 days | 675ml | 0 out of 4 days | Tea, soup, nutritional supplement water, juice | |
| Bill | Yes | 0 out of 3 days | 716ml | 0 out of 3 days | Tea, soup, water | |
| Cara | Yes | 2 out of 5 days | 630ml | 0 out of 5 days | tea, water, juice, nutritional supplement | IV fluids as part of the total intake on one day |
| Daisy | Yes | 2 out of 3 days | 717ml | 2 out of 3 days | Tea, water, juice, coffee | IV fluids included in the totals intake |
| Finn | No | 2 out of 4 days | 538mls | 0 out of 4 days | Water, tea, soup, juice | |
| Gail | Yes | 4 out of 4 days | 1118ml | 1 out of 4 days | Water, tea, soup, juice | IV fluids included in total intake |
| Hana | Yes | 4 out of 9 days | 823ml | 0 out of 9 days | Tea, soup, water, juice, coffee | |
| Ivan | Yes | 2 out of 6 days | 638ml | 0 out of 6 days | Nutritional supplement tea, soup | IV fluids included in total intake |
| June | Yes | 5 out of 21 days | 738ml | 9 out of 21 days | Nutritional supplement Fanta, soup, water, tea, milk, coke, juice | |
| Kay | Yes | 5 of 15 days | 806ml | 1 out of 15 days | Water, tea, chocolate, soup, juice, coffee | IV fluids included at start of admission |
| Lily | No | 2 out of 3 days | 743ml | 0 out of 3 days | Tea, water, coffee, soup | IV fluids on 1 st day |
| Mae | Yes | 8 out of 14 days | 874ml | 2 out of 14 days | Water, tea, juice | |
| Please note, this data was not collected for Eddy who was a pilot participant | | | | | | |

The charts were not always totalled. The types of fluids consumed were mostly what was available on the ward and the fluids offered infrequently recorded, even with the Fir participants who had a 1:1 with them, so staffing is not likely to be the reason for omissions. Nurses across the wards suggested fluid charts were not always completed accurately:

“We have fluid balance charts but a lot of the time they're not filled in accurately [...] especially if you've got a patient like how [Mae...] was today, because your main focus is just calming her down, not writing down every single thing she's drinking, [...], she can probably go like two hours without having a drink and we haven't noticed because we've been so distracted.”
(Nurse, Mae, Fir, interview.)

This indicates other aspects of care may be prioritised over fluid balance. Another issue may be that hosts delivered most drinks but completed no documentation of drinks accepted or declined. On occasion, nursing staff documented intake by asking OPLWD directly:

17.41: A nurse is at Ivan's bedside [...] she picks up the nursing notes and asks him how much water he has had and seemingly documents the response. (Ivan, Elm, Obs2, fieldnotes.)

Across the wards there were nursing entries about hydration on most days. Often, the language used to describe hydration had limited or no description, for example only the words: “eating and drinking” or “E+D” were documented. The descriptions which were used are included in table 6.5.

Table 6.5 Nursing descriptions documented for hydration in MDT clinical records

| Ward | Nursing descriptions documented for hydration in MDT clinical records |
|-------|--|
| Birch | "Poor" "fairly taken" "normal amounts" "small amounts" |
| Elm | "Drank well" "moderate amounts" "encouraged as able" "adequately" "variable" "fairly well" "as tolerated" "around 8 to 10 glasses" |
| Fir | "drank well" "maintained" "tolerated" "poor" |

Elm had the largest variety of hydration descriptors, although only one was specific:

"Encouraged to eat meals served and drink around 8 to 10 glasses of water"
(Eddy, Elm, MDT clinical records.)

It was rare for nurses to document hydration care plans, when a plan had been documented it was to "encourage" oral intake. On no occasion was the fluid balance referenced in the nursing entries in the MDT clinical records. A factor affecting descriptions may be that HCAs spent most time with OPLWD but do not contribute to the MDT clinical records:

"The nurses write all of the notes. So the nursing assistants I don't think feel empowered to write in the notes and often they're the ones that know more about the patient. [...] How much they've drunk, if they opened their bowels [...], how many times have they tried to help that person [...] a lot of times [...] the nursing assistants [...] know that more than anybody, but I don't feel like they're empowered to write down or they feel like they can."
(OATN, Birch, interview.)

There were rarely other MDT members present in the bays, so the opportunity for this information to be shared verbally between staff seemed limited. Staff

discussed using verbal communication to communicate care needs, for example through a 'huddle' or handover:

"In our safety huddle and in our handover, we basically hand over all the patients that have dementia so everybody will know [...] and then they will be assisted with like eating and drinking." (WL, Fir, interview.)

I did not observe huddles, so cannot comment on their content. A range of staff: medical, nursing, and physical and occupational therapies, were observed to verbally share care plans which were not documented in the clinical records between themselves, perhaps as an alternative to documentation. Or clinical decisions were made with no documented or verbal rationale, as described in section 5.4.3.4 (when the doctor prescribed IV fluids without communicating a rationale). Handovers were observed if they were conducted in the immediate environment of the OPLWD:

8.21am: Amongst other information the nurse hands over to, "encourage fluid intake" (Hana, Elm, Obs1, fieldnotes.)

Shortly after, a nurse has this interaction:

8.44am: A nurse attempts to wake Hana up, using a soft voice: "Hana, what would you like?" and lists breakfast options, [they] encourage and assist Hana to sit up [...]. Hana says: "I feel dizzy" Nurse response: "ok".

8.45am: Host attends: "what would you like for breakfast? Porridge? You want tea?"

Hana: "no"

Nurse: "no fluids?"

[...]

The host returns: "porridge, no tea, no coffee, just Porridge" and puts the tray down.

The nurse puts it on the table in front of Hana and ask:, "any sugar?"

Hana says no. The nurse leaves [...] (Hana, Obs1, Elm, fieldnotes.)

I observe until 12pm and despite the recommendation at handover Hana only receives two attempts for hydration care, alongside other tasks. Once the nurse offered a drink with medication, and the HCA offered Hana a drink when taking her vital signs; she accepted on both occasions.

In addition to clinical records the communication board, situated above a patient's headboard was another location where staff could share information:

“[The] communication board, is a great tool to pass the message to them or handovers [...] It's just above the patient's bed.” (Nurse, Ivan, Elm, interview.)

The board could be used to document information about a person, but this was rarely observed. This was even for potentially essential information, for example, there were two participants whose first language was not English but neither had their first language documented. Another example was the names documented above Eddie and Kay's beds were not their preferred names; despite Kay regularly, verbally telling staff her preferred name it was never amended.

One occupational therapist explained that it was a challenge knowing which OPLWD required prompting with hydration as it was not documented on the communication board. However, when asked about communicating any needs they identified, they suggested they would potentially utilise verbal communication only:

OT: *“So [...] when [...] I assess the patient, I will see how their cognition impact[s] on them [...]*

Interviewer: *And how do you record that? [...]*

OT: *Uh, I think sometimes I will just write it in the notes or just do a verbal* (OT, Ivan, Elm, interview.)

There was little information available about the OPLWD's preferences or needs for food and fluid intake, discussed further in section 6.3.4; when they were present they were not always utilised. One HCA expressed they did not always trust the communication received from other staff, so preferred to find out information in their own way:

"I looked after a person a couple of days ago, they tell you something else when you are getting a handover, if you did everything you are being told while they are handing over to you, and react on that you wouldn't recognise that person [...] at least take your time to do self-assessment and deduce your facts when you are with them [...]" (HCA, Bill, Birch, interview.)

This demonstrates staff may gain their information in-the-moment, rather than consider information communicated by others.

6.1.3 Communication between staff and relatives

Most participants had relatives who visited them, though staff did not always interact with the relative when they were present. The hospital-wide Carer's policy stated relatives should be identified, and discussions should take place about the level of involvement they wished to have with their family member's care. The policy also included a 'Carer's Card', which enables the relatives access outside permitted visiting times but only the Elm WL discussed this:

"[We have the] Carer's Card, initiatives [...] to try and gain [...] as much information [...] allowing them [relatives] to stay overnight [...] But, balancing it, because you've got the fire regulations with the fire officer saying: "Why are you allowing everybody to stay?" You have to be sensible, if someone is really distressed you need to ring their next of kin and [...] say: [...] Can you come in? What would you do in this scenario?" It's about communication [...] if we think they're a genuine carer, you can [...] tap out the Carer's Card and go: 'There you go this will give you access in the front

doors [...]. But [...] we need to see a real understanding that they're there for them, [...] so there are specifications.” (WL, Elm, interview.)

This interview indicated that there may be difficulties navigating the collaborative relationship between staff and relatives within the hospital. On Elm, Gail's relatives had not been asked about Gail's preferences but also felt staff could share more information:

“I don't know how much she's drunk [...] I could see staff are really busy. But [...] It would be nice to be told that she's had some water.” (Relative, Gail, Elm, interview.)

Gail's relative heard staff asking Gail her preferences but had not been included in this conversation. Mae's daughter said she had verbally communicated Mae's preferences to staff but had not seen anything documented. There were differing experiences among Birch relatives:

“Quite soon when Daisy arrived on this ward [...] someone came along and asked questions about likes and dislikes.” (Relative, Daisy, Birch, interview.)

However, they also felt staff interacted with Daisy less when they were visiting:

“I noticed that when I go away and then come back half an hour later things have changed and they've done something while I was away. I don't understand why they don't ask me to go for a walk for five minutes if they want to do something.” (Relative Daisy, Birch, interview.)

Observations indicated when relatives were present staff seemed to reduce their contact with OPLWD and subsequently their relatives. Gaining information from relatives about the OPLWD was highlighted as useful by one nurse but few staff identified this in interviews:

“Preferences [...] for example with [...] that group of patients that we have a hard time understanding their language. Like if [...] they're[...] a different race and most of us here is speaking English, but some of them has dementia and they return back to their previous memories [...] So sometimes we cannot understand them [so...] I speak with their relatives, but sometimes they're not [...] around [...] or not that available [...] So sometimes you're really having a hard time and with the fact that we're really juggling a lot of tasks during our work, it's hard.” (Nurse, Elm, Ivan, interview)

This nurse recognised that getting information from relatives could be beneficial but also that access was not always possible. Cara's relative explained members of the MDT, excluding nursing staff, had collected discrete information, specific to their role, but excluded information about hydration:

“[...] In terms of drinks, no, no, but actually perhaps it's a question they should ask. Well, the OT has asked me [about her usual routine] but as far as the nurse is concerned, they haven't really asked much about her routine. [...] the consultant asked me a bit about mum's routine [...], in terms of pain management, but not in terms of food or drinking and the OT asked me about food today because mum's not eating very much, but that's usual for her [...] But [...] hydration didn't come up, which is quite strange really, if you think about it.” (Relative, Cara, Birch, interview.)

Staff asking for information about Cara only relevant to their role reflects the compartmentalised roles staff have, discussed in section 5.4, and that no-one's role included asking about hydration. Doctors were the only staff observed to meet relatives in a planned way, away from the bedside. A dietician documented a phone call with Eddy's relative about his needs, identifying:

"Pt needs encouragement to eat but also help with identifying what to eat/how to eat." (Eddy, Elm, MDT clinical records.)

This documentation of relative's views of intake needs was unique but once again did not include hydration. Absence of documented information may not indicate how much staff know about the person according to the OATN:

“So family are just coming in all the time and [...] they're just drip-feeding information [...] without the nurses realising [...] So the family are probably just saying simple things like, "oh, she hates that" or "she enjoys this" or "she's normally more awake than that" and "why she's so sleepy?" and having those family there, it's that constant reminder of, OK, "What are they like?" (OATN, Birch, interview)

However, even if staff find this information out during a shift, there is the risk this information is lost when they finish, due to the reasons discussed in section 6.1.2.

6.2 Action strategies

Action included staff providing direct support to the OPLWD, leadership and delivering associated care which supported hydration care. Action was often used alongside communication strategies.

6.2.1 Providing direct support with hydration to OPLWD

The action strategies staff reported were: finding out the person's preference, observing the person's response to drinks, monitoring intake, pouring drinks, taking drinks to the person, leaving drinks within reach and placing a drink in the person's hand or holding it to their lips. Nurses, HCAs, hosts and on one occasion an OT took actions to deliver hydration care including passing a drink or putting drinks within reach. Like communication, action strategies mostly happened alongside other care tasks or during a meal:

17.10: Two nurses arrive, one says: “can we sit you up so you can enjoy your soup?” They close the curtains [...] the curtains open, Alan is sitting

up in bed with the table in front of him, which is now clear of items. (Alan, Obs2, Birch, fieldnotes.)

Drinks were mostly brought to the OPLWD by the host during a drinks round:

16.00: Host stands in the bay and says: “tea, coffee, tea, coffee” Kay says: “tea please.” The host puts a tea on the table. (Kay, Fir, Obs3, fieldnotes.)

However, once the OPLWD had a drink, the actions of different staff often did not link to promote hydration. For example, when Kay received this tea from the host, she also had a 1:1 HCA with her, who had her eyes closed from time-to-time. A few minutes after receiving the tea, the HCA encouraged Kay to get into bed, Kay declined. Kay did not drink the tea and the HCA only provided Kay with one verbal prompt 16 minutes later:

16.16: Kay picks up her cake and the plastic makes a noise; the HCA wakes up and says: “do you want to eat it?” Kay says yes and smiles, the HCA opens it for her. HCA says: “do you want it with tea or coffee?” Kay replies: “no, just on its own” the HCA hands it to her and she eats. (Kay, Fir, Obs3, fieldnotes.)

There were many times across all wards when drinks were provided and the OPLWD was left for quite some time before any staff assessed whether they required assistance. There was one occasion when the host checked the drink was satisfactory before leaving:

12.44: [...] Host returns and shows Daisy the drink inside the mug, while saying: “coffee, it’s a strong coffee” and then shows Daisy’s relative. Relative: “that’s probably too much milk” The host seems surprised: “too much?” and shows Daisy who says: “it’s OK” (Daisy, Birch, Obs3, fieldnotes.)

One HCA combined action and communication strategies while relatives were present to provide successful hydration care:

14.43: HCA returns [...] saying; "hello trouble" [Bill and his relatives] all laugh. The HCA crouches to Bill's eye level while talking to him, asking if he would like a drink and gently persuades him to have one. Bill agrees to a coffee, the HCA asks how he takes it and Bills relative replies: "milky, no sugar" the HCA repeats this and leaves, saying: "I will get that" [...] HCA re-enters [...] walks to Bill, puts a napkin under his chin, saying: "here's your coffee." Bill says: "thank you" and takes the coffee with both hands. The HCA also offers his relatives a drink: "are you sure you don't want anything?" [...] On leaving the HCA says: "coffee, milky, no sugar" and smiles. Bill is drinking coffee in bed [...] talking with his relatives. (Bill, Birch, Obs1, fieldnotes.)

When relatives were present the OPLWD were observed to consume fluids more readily, however, staff did not always take advantage and offer the person a drink at this time.

Staff across the wards spoke about their role recognising a person's independence:

"Lily [...] she's a bit independent. Just she knows what she likes. So even when we try to encourage her or like remind her to drink, she says: "Oh, I like to do it my own way." (StN, Lily, Fir, interview.)

Some were cautious not to impact negatively:

"As much as you want to help you don't want to take their independence away from them. So, [...] I'm asking him: "Do you mind me to do this, [...] that? Is that OK if I help you?" (HCA, Bill, Birch, interview.)

I did not witness many staff engaging in dialogue about the level of support the OPLWD wanted with hydration care. There was no documentation of a person's abilities relating to hydration prior to hospital admission and staff did not report this within interviews, so it is likely any evaluation of a person's abilities are based on their functioning in-the-moment. An HCA spoke about how they cannot 'force' a person to drink and the associated emotions when an OPLWD refuses:

“It's quite difficult when [...] they always refuse, you find it really frustrating wondering if there's anything else you can do to make them actually want, [...] to drink, because [...] it's really necessary for them to drink but if they keep refusing and of course, you can't force them [...], so that I find a little bit unsatisfying if I feel I didn't get them to drink enough, [...] You can only encourage them [...] keep offering and hopefully they will take it [...].”
(HCA, Hana, Elm, interview.)

This demonstrates that hydration care can be associated with challenges and emotions for staff.

6.2.2 Leadership

Leadership actions were discussed in interviews but not always visible. One Birch leadership strategy felt to contribute to hydration was the soup round:

“We do a soup round twice a day and it's always the nurse in charge [...] first of all, the soup's really good, so you recommend it, [...], it's a really good exercise [...] because [...]it is a] systematic [way of] going through every single patient [...], seeing, [...] clinically, how do they look? We may pick up on things [...]like] they're not very comfortable[...] it's really nice just to go and talk to patients [...] meet families [...],and if there's any issues they [know] where they can find us, seeing how people are managing their fluids, [...] I don't really understand why it's not just a standard thing because I think if we can do it here, twice a day, then I think it should be done everywhere [...] And you know, the nurses then see you and they can ask you stuff. So, it [...] has a lot of benefits.” (WL, Birch, Interview.)

The soup round also took place on Fir but was mainly undertaken by an HCA or StN. The Elm WS had not implemented it:

“Now we haven't started the soup round, some wards do [...] and we are going to do it but, [...] it's OK to do the soup round when all the patients will sit up nicely for you, our patients aren't [able to...] so it's a case of: “Am I sitting [them] up properly, making sure they won't aspirate?” Or am I actually

giving it out? And I'd like to be giving it out but feasibly I don't have enough staff.” (WL, Elm, interview.)

Other than the Birch soup round, across the wards there were few interactions observed between ward leaders and OPLWD. If the Elm WL was worried about a patient, she reported being directive or modelling to HCAs how to assist the person, but I did not observe any modelling from WLs. Birch and Elm WLs also reported completing audits of clinical records:

“So, it’s just trying to get the mind set around, thinking and talking about, [the fluid balance charts] the first thing I will look at on my quality review and I will circle it with a big red biro as if to say, at midnight I want this filled in. And I think it’s just about constantly doing that.” (WL, Elm, interview.)

However, I did not observe any circled fluid charts.

6.2.3 Associated areas of care

There were some areas of care which could indirectly affect hydration care, even though they did not directly involve providing hydration care. The registrar and the Elm WS discussed the link between oral hygiene care and hydration:

“[...] One of the things that is really important is good oral hygiene, it’s something [...] that loses a bit of context in an acute medical admission, [...] like brushing your teeth or [...] care of your tongue. You can see people build up [...] poor oral hygiene and can develop coated tongues [...] that then can really put people off eating and drinking, changes the taste in the mouth. [...] that’s another thing that we can proactively do as healthcare professionals to try and avoid that building up. And [...] thinking about the [...] effect on constipation. So, if people become dehydrated, they’re more prone to develop constipation, which can then make people develop hypoactive delirium and maybe preclude them from eating and drinking even more. So, you get a bit of a vicious cycle.” (Registrar, Elm, Birch, interview.)

As care that took place behind a curtain was not directly observed, I do not know the extent of oral hygiene care for OPLWD. During one observation, oral hygiene was obviously being carried out and it seemed distressing for the OPLWD as staff did not know if the person's teeth were false:

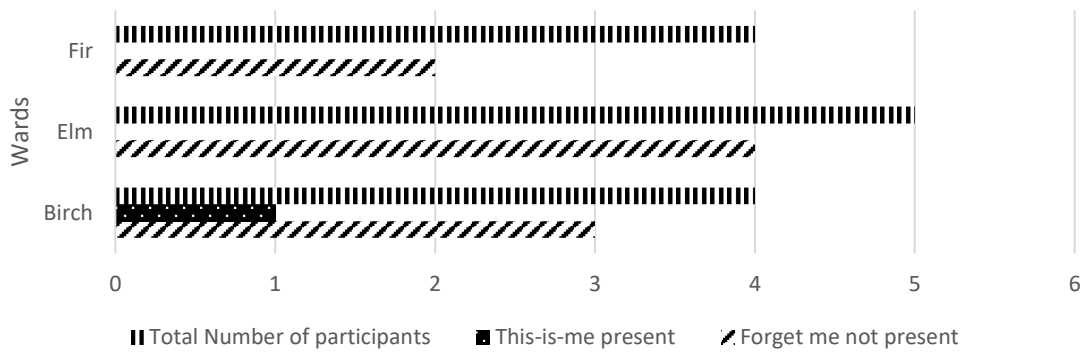
12.58: HCA1 returns with a bowl [...] HCA1 says to HCA2: "I want to brush the lower teeth." HCA2 says to June: "It's dirty darling." June screams out. Both HCAs are discussing whether the lower teeth are false [...] and trying to take them out. (June, Fir, Obs1, fieldnotes.)

Shortly after they discover June's teeth are real. This demonstrates that in addition to hydration care, other aspects of fundamental care may be lacking documentation about an individual's needs.

6.3 Resources

The hospital provided wards with standardised resources to aid dementia or hydration care, such as an identification system for people diagnosed with dementia, called the 'forget-me-not' or an identification system for patients that require additional help with eating and drinking, using a 'red jug, red tray' as well as a documentation system for information about a person, called This-is-me. The drink and cup choices available and access to drinks were also important resources. Training, knowledge and staffing were also resources required for successful hydration; these were discussed in section 5.4.2, so are not repeated here. Figure 6.2 presents the implementation of each identification strategy on the wards.

Figure 6.2 Use of standardised strategies to aid dementia care per ward



Each strategy is discussed individually.

6.3.1 Identifying an OPLWD

If a person had a diagnosis of dementia an image of a ‘forget-me-not’ flower was placed above their bed, this was the most-used strategy on all wards (see figure 6.2). Staff rarely mentioned the ‘forget-me-not’ in interviews, possibly indicating they do not connect the identification of the OPLWD’s diagnosis with their hydration care. However, the host who had received dementia training spoke about the symbol:

“When I do the tea round and I see the flower sign by the bed that means that the patient’s got dementia.” (Host, Ivan, Elm, interview.)

Thus, their dementia training had affected their awareness of OPLWD’s needs.

6.3.2A documentation system to record information about the OPLWD

The documentation system to collect information about the OPLWD’s preferences and life history was called This-is-me. This-is-me usage was low with only one active document found in use (see figure 6.2), on Birch. During two separate Elm observations I witnessed staff completing a This-is-Me, once by a student nurse and once by a relative’s support (RS) staff member. They had different approaches

to completing them; the student nurse took a task-orientated approach involving minimal communication with Hana and none with her family:

14.36: StN says: "I'm filling out forms today, can you tell me your daughter's name?" She adds it to the This is me card.

The StN tells an HCA that she is struggling to fill [the This-is-me] in as she does not know the patients that well. I ask the StN how she came to fill out the 'This-is-me,' she replies: "it's probably in relation to a national strategy." I ask about why it is being completed today, she said she asked the WL if there were any jobs to do and was asked to fill them out. The HCA close-by says she has never seen the 'This-is-me' before but thinks they are a great idea. (Hana Obs3, Elm, Fieldnotes.)

This example highlights that ward HCAs may not know about the existence of the This-is-me which could be a reason for a paucity in completed documents on the wards. The completion of Ivan's This-is-me in collaboration with his family contrasts with the completion of Hana's. A carer's support staff member had been talking to Ivan's family about Ivan's hospital experience and gave them a blank 'This-is-me,' while encouraging them to fill it out; in the process, Ivan and his family had an engaging conversation about Ivan's interests and the family demeanour changed from seeming frustrated with the care experience to being full of praise, particularly about the carers support staff member. That was the last observation I completed with Ivan, so I am unsure how the information provided by his family was utilised by staff. Following the completion of Hana's 'This-is-me' I carried out another observation, however, it was no longer present, so appeared to not be in use. In contrast, Daisy had a 'This-is-me' completed which was being utilised with benefits:

“So [...] we had no idea that she liked black coffee, with two sugars or with no sugar sometimes until [her relative] came in [...] So, [Daisy] says, “I’d like a cup of tea” but what she actually means is black coffee, and we didn’t know that. The HCA who was looking after her was able to go through that with her next-of-kin.” (Nurse, Daisy, Birch, interview.)

The reason for the low use of the ‘This-is-me’ remains unclear.

Most participants had relatives that visited so it is unlikely the problem was access to the information. However, as discussed in section 6.13 there may be barriers to staff engaging with relatives when they are present. When I discussed the This-is-me with relatives other than Daisy’s they were not aware of the document:

*“**Relative:** I haven’t filled this in [...] I haven’t seen this before so I don’t know.”*

***Interviewer:** [...] So when the staff asked you her preferences [...] did they write it down somewhere [...]?*

***Relative:** “I don’t know, I haven’t seen anybody write it down.”* (Relative, June, Fir, interview.)

Occasionally, there was handwritten information about a person’s preferences or needs displayed above the person’s bed, but it was unclear who documented these. I assumed preferences were documented by relatives as the information was handwritten and looked different from most clinical documentation above the person’s bed, which was usually laminated. The four participants who had this information were on Elm or Fir and three had a dietician care plan, so it was possible the families had documented the preferences following dietician advice. However, the information when present was not always utilised:

15.33: June’s visitor asks the HCA if she ate her lunch. The HCA says no. The visitor asks what she had. The HCA says cottage pie. The visitor says:

“She doesn’t like that, that’s why we put up a list of things she does like.”
(June, Fir, Obs1, fieldnotes.)

Staff also did not acknowledge instructions when they related to a potential risk. Ivan was ‘nil-by-mouth’ due to an upcoming investigation; a laminated A4 piece-of-paper above his bed displayed “NBM”:

12.48: Host arrives, walks towards bed and asks: ‘Tea?’ Ivan’s relative replies: “he’s not allowed as he’s nil by mouth.” Host leaves. (Ivan, Elm, Obs3, fieldnotes.)

Similar instances were observed with healthcare staff:

8.39: The nurse asks Eddy if he would like toast, the HCA says from the adjoining bay: “Puree” (stating Eddy’s visibly documented dietary requirements). (Eddy, Elm, Obs1, fieldnotes.)

In both situations someone was present who noticed these potential hazards, which was fortunate as there were long periods of time when OPLWD were alone. Where information was known, staff did occasionally use it in conversation. The OATN felt Birch staff enjoyed sharing knowledge:

“[...] Staff love to tell me what they’ve done for their patients [...] they [...] say, ‘I’ve just spent the morning with this man, and I’ve learned he used to work on this market’ [...] when they have taken the time to deliver PCC, they like to report it [...] and I share [...] information back with them. [...] it’s building [that] relationship, between me and that nurse [...] so then when I come back and say, “can you do this for them?” or “actually I notice she’s not drinking as much.” they’re more likely to do it because we’ve got that relationship. But it’s also nice for them to understand the patient’s a person. [...] it changes the dynamic between the patient and the HCA [...] they just think it’s a nice story to come and tell me, what they don’t realise is [...] it makes their delivery of their care very different.” (OATN, Birch, interview.)

The view that finding out information is “nice,” rather than an essential component of care was a recurring thread, with aspects of PCC being seen as “nice” or additional extras rather than an essential aspect of providing care, which may also impact the completion of the ‘This-is-me.’ The bank HCAs on Fir felt they did not have sufficient information to fulfil all the tasks required in a way that suits the patient. One said a lack of information happened across all the ward areas:

“I think [it is] just important to mention anything that could get in the way of any sort of communication or care [...] especially with [...] dementia, some people get to the point where they can’t verbalise it, so then how am I meant to know, if I’m not told either, or it’s not written down in the notes [...].” (HCA, Kay, Fir, interview.)

Although they felt more information would be useful, they did not consider finding it and documenting it themselves. It may be possible that HCAs do not feel it is part of their role or do not feel empowered to fill out the ‘This-is-me.’ A desire for more information was not shared by the substantive HCA on Fir, who focussed on safety and preventing falls as their role.

6.3.3 Identifying people who require additional help with eating and drinking

Nursing staff across the wards identified the “red jug, red tray” system:

“So, our policy is if they need assistance with eating and drinking we use the red jug and the red tray [...which] are basically one of the indications that the patient will need assistance with eating and drinking.” (WL, Fir, interview.)

The implementation of this system on all wards was low, with no consistent use with any participants. The Elm WL linked hydration to meals and implemented a “meals matter” project to raise awareness:

“So, on fluid intake, the first thing that I say is making a big thing about meals is important [...] because it's [...] nutrition/hydration [...] the ward has done a huge project on “meals matter,” the red trays easily identify and provide equipment to those that need a lot more help.” (WL, Elm, interview.)

The WL quote aligns with the hospital-wide findings that mealtimes were prioritised, or hydration care was considered as belonging with mealtimes. Some staff felt there were resources that could promote independence that were not available including colour coded jugs, cups, trays:

“Maybe, making the jug like a different colour, or [...] the cup handles [...] so that they are reminded more to [...] grab the cup [...] I do have patients who have poor vision and [...] dementia [...] because the jug is quite clear they don't really know where on the table the jug is [...] sometimes that's how they spill the jug and then they're like, “oh, I'm really sorry, I spilled” ... and their mood changes because they feel horrible that they spilled [...] the water.” (StN, Lily, Fir, interview.)

However, as the red jug, red tray system was available for use, it may indicate that not all staff know about the availability, how to access them or that they are not supportive. All participants had a hospital table by their bedside, the only items always present were clear jugs of water; there were no red jugs observed. When mugs were present, they were usually blue plastic; red plastic mugs were only observed on two occasions - on Elm - and one of these was for Finn who was independent with drinking. It was unclear if the red mugs had the same importance as red jugs or red trays.

6.3.4 Choices and availability

Staff and patients' opinions on the choice of drinks varied, some felt more options would be beneficial. There were differences between the choices offered and what a host reported was available:

“Coffee, hot chocolate, lots of options for herbal tea, squash [are available]”
(Host, Lily, Fir, interview.)

However, only tea or coffee were observed to be offered during “drink rounds.”

This lack of choice was also reported by an OPLWD:

“No one has asked which drinks I like ...I was only offered water [or] tea, but I like milk especially at dinner that's why I drink at home I like yellow and red top milk, I also have half a pint with my dinner” (Finn, Elm, interview.)

Furthermore, it did not appear all staff were aware of the full choices:

“We're quite good I think at offering people tea or coffee but it is literally tea or coffee or water. So there's no other [...] provisions made for anyone, and it's not just patients with dementia, it's anyone who might want orange squash or [something else], but we have to make do with what we have at the end of the day, but I guess choice isn't great.” (WL, Birch, interview)

Other staff felt relatives had a role to provide choices which the hospital did not, highlighted in section 5.4.3.9. On the few occasions when staff attempted to make drinks outside of the routinised drinks round, they found difficulties with lack of resources:

9.07: The nurse asks: “do you want some water?” Alan replies: “I’ll have a cup of tea” Nurse: “oh, a cup of tea, I can get you that.”

[...nurse does not return with tea]

9.27: As the host walks past the nurse they ask the host if they would make a cup of tea for bed number x [...Alan’s bed], the host does not reply. The nurse apologises and says: “there were no teabags in the beverage bay.” (Alan, Obs1, Birch, fieldnotes.)

The host does not bring Alan a drink. However, an HCA does bring Alan a polystyrene cup of tea at 9.55am. The host next attends an hour later during

the drinks round, they say: “tea, coffee” to the bay but Alan has his eyes closed and does not appear to hear.

This was not an isolated example, there were many occurrences of missed opportunities for hydration like this. The nurse’s experience emphasises the physical barriers healthcare staff experience when attempting to access drinks (discussed in section 5.3.2).

In addition to limited drink choices, there was only one occasion where a choice of cup was offered, which was via the OPLWD’s relative:

18.00 The host walks up and down the bay saying: “tea, coffee.” Gail’s relative repeats this to Gail [...] who says she would like a cup of tea. Gail’s relative tells the host. The host offers a choice of cups to the relative (polystyrene cup or a plastic mug with a handle). Gail’s relative asks Gail, but she doesn’t really answer. Gail’s relative chooses: “Oh yes that one” and points to a mug with a handle. Caterer: “Yes while sometimes this one [polystyrene] is good, it depends on age.” (Gail, Elm, Obs3, fieldnotes.)

The host indicated that the polystyrene cup was not very good for older adults, but this was on Elm, the elderly medicine ward, where polystyrene cups were regularly provided, without a choice of drinking utensil offered. During an observation there was a large bite-mark taken out of Eddy’s polystyrene cup, indicating this was not the most suitable cup for him; this cup remained on his table until the next observation period eight hours later but was filled with rubbish by this time.

One relative spoke about the expectation to have a jug of water present as an essential aspect of care and the disappointment when Gail was moved from Birch to Elm and no water was present:

“When we were first transferred [...] I knew she was really dehydrated [...] So, I was trying to get her to drink quite a lot [...] I asked someone for

water because there was nothing and they looked at me and said: "yeah, I'll get you water" and they didn't [...] we didn't have to wait long, because I spoke up and I asked [...] a different nurse [...] and she said, "of course darling" and went off and got it. But the first one never did come back and say, "oh, I'm sorry. I was meant to get you that water [...]" so I was a bit disappointed with that because I would have thought you move her [...] your number one thing is to check that they've got water at their side, [...]" (Relative, Gail, Elm, interview.)

Due to most participants sitting or lying in bed, it was unclear from observing them if they would be able to reach the water jugs or drinks on the table; mostly they did not attempt to. During one observation Eddy did not have a jug on his table, it had been placed out of reach on a set of drawers, demonstrating the environment around an OPLWD is not always set up to support hydration, which is discussed next.

6.4 Environmental aspects

There were two aspects of environmental strategies and barriers: the social environment and the physical environment.

6.4.1 Social environment

This section includes the staff approach to interactions, consideration of an OPLWD's psychological needs, engagement and occupation, which all influence the social environment and could facilitate successful hydration care.

Although most interactions were rated as 'positive care,' (see table 6.6) some OPLWD experienced more positive social interactions than others. Relatives spoke about normalising hydration in hospitals, or making hydration sociable as a strategy to improve hydration, which contrasted with most staff:

“It would be helpful if the 1:1 with Mae also had a cup in her hand when Mae has a cup of tea, even if they don’t drink from the cup” Mae’s relative says sometimes she holds a cup that she doesn’t drink from to encourage Mae to drink also. Mae’s relative says this would mean the 1:1 could say “let’s have a cup of tea” rather than, “you have a cup of tea” and therefore make it more of an event. (Relative, Mae, interview by telephone.)

Although infrequent, when staff did attempt to make hydration sociable or a more engaging experience it was successful.

Table 6.6 QUIS rating by ward in percentages

| | | | Quality of interaction schedule rating | | | | | Total |
|------------------|-------|----------|--|----------------|---------------|---------------------|----------------------|-----------------|
| | | | Positive Social | Positive Care | Neutral | Negative Protective | Negative Restrictive | |
| Ward Name | Birch | N (%) | 13 (7.2%) | 140 (77.8%) | 17 (9.4%) | 7 (3.9%) | 3 (1.7%) | 180 (100.0%) |
| | Elm | N (%) | 27 (10.8%) | 175 (70.0%) | 25 (10.0%) | 1 (0.4%) | 22 (8.8%) | 250 (100.0%) |
| | Fir | N (%) | 59 (19.6%) | 173 (57.5%) | 34 (11.3%) | 10 (3.3%) | 25 (8.3%) | 301 (100.0%) |
| Total | | N (%) | 99 (13.5%) | 488 (66.8%) | 76 (10.4%) | 18 (2.5%) | 50 (6.8%) | 731 (100.0%) |

The observational data suggested the type of interaction received by the OPLWD was due to the staff approach rather than individual characteristics of the OPLWD. Observations with Eddy demonstrated this well as on the same day he experienced either positive social interactions and positive care interactions, or negative restrictive interactions, depending on the staff member approaching him:

10.53: Eddy tries to stand, HCA says: “sit down” multiple times, then leaves. Eddy stands. The HCA returns [...] and says: “sit in the chair” and starts stripping the bed [...] without speaking. Eddy stands again, HCA: “Sit down, behave yourself.”

11.17: Eddy stands up and looks unsteady, [...] I call for the HCA. The HCA starts to take Eddy for a walk and tells another nurse why he can't leave the bay (he is on his own). A visitor walks past and asks if Eddy is OK [*then speaks in Eddy's first language...*] She says Eddy told her he needs to find his wife and is asking where he should go.

11.20: A nurse arrives and takes over from the HCA, the nurse takes Eddy for a walk [...] talking to him [*In English*] the whole time, [...]. The nurse offers him a drink on the walk when they are near the water machine, Eddy accepts. The nurse and Eddy return and Eddy sits in his chair. (Eddy, Birch, Obs1, fieldnotes.)

During the walk the nurse successfully encouraged Eddy to drink, later the nurse reflected that occupying Eddy with walking was a strategy to provide fundamental care. This example demonstrates how hydration care and PCC interrelate. The HCA making the bed was not on a 1:1 with Eddy, which may be why they did not take him for a walk, however, later, despite knowing the cause of Eddy's distress, the HCA did not use this knowledge in a thoughtful way:

16.47: Eddy stands up when he sees the domestic, the HCA goes over and says: “It's not your wife.” Eddy has taken his socks off and the HCA wants to put some more on him. [...] Eddy is speaking in his own language and seems distressed. The HCA asks him to sit down. (Eddy, Birch, Obs2, Fieldnotes.)

[Later, Eddy is crying, the HCA continues telling him to sit down. The nurse intervenes and provides a soft voice, reassuring touch and presence. The nurse offers him a drink and is visibly pleased when Eddy drinks independently]

19.58: Eddy drinks, the nurse says to the HCA: "Look he's drinking." HCA replies: "Yes he does drink if you leave it, even with tea." (*I document that: "I feel frustrated because this is not what I observed"*) Eddy reaches over and tips his cup up, as it's empty. (Eddy, Birch, Obs2, fieldnotes.)

There is a noticeable contrast between the task-focussed, safety-orientated approach which the HCA takes and the calm, soft and engaging approach of the nurse which seemed to focus on enabling Eddy, and how Eddy responds to these approaches. The examples demonstrate how responding with empathy to an OPLWD's distress can also positively impact their hydration care and the care OPLWD receive is often dependent on the person interacting with them, influenced by the staff approach to interactions.

Task-focussed communication could lead to the OPLWD's expressed psychological needs being ignored. Lily and Hana both communicated concerns about continence, which impacted on intake, but it was not clear that staff acknowledged them:

The student offers Lily some vegetable soup, "would you like some, it's vegetable soup?" Lily refuses, the student asks if she is sure, saying she could leave some. Lily says, "there could be a flood" the StN asks, "flood?" Lily pats her stomach and says she cannot have too much liquid and smiles. The interaction ends. (Lily, Fir, Obs1, fieldnotes.)

Hana was distressed about going to the toilet frequently and on one occasion thought she had left a wet patch on the bed, to which she said something in a different language to her relative who replied: "you need to keep drinking." The staff were not observed to engage with her concerns about this. Even when attentive

healthcare staff were present, when focussed solely on 'the task at hand' this could impede the OPLWD's expression of emotional needs:

8.36: HCA moves closer to Gail [...and] picks up the cereal packet [...] HCA says: "Hello Gail, how are you?" Gail [says...] she is: "not sure about what's happening," The HCA explains that she's in hospital. Gail says she knows that and begins to expand on how she feels. HCA interrupts and says, 'well have some breakfast first', and asks if she wants sugar in her tea. Gail says no thanks. HCA repositions tray and table in front of Gail, putting milk in the cereal, leaves to assist another patient. (Gail, Elm, Obs2, fieldnotes.)

Gail does eat the cereal but does not drink the tea. Occasionally, the OPLWD requested support from the 'wrong' staff member which added further complications:

8.19: The host attends, bends down and asks Cara what she would like for breakfast, she responds: "Pain." The host continues to offer her breakfast options, but Cara says nothing. (Cara, Birch Obs1, fieldnotes.)

When the OPLWD communicated with the 'wrong' staff member it was unclear if these needs were communicated to staff who would be able to support them. These unmet needs potentially contributed to distress. When a person was distressed, they often missed out on hydration:

17.24: The HCA continues encouraging June to drink the [supplement drink] but June says: I don't like it." HCA: "You don't like milk?" June: "I like milk but not that milk." June picks up another polystyrene cup and asks: "what is this?" HCA: "it's water" June: "No it isn't" looks at it and takes a sip. June tries to stand up the HCA encourages her to sit down. [...] June seems to be getting anxious and saying that she needs to look after her mum, she wants to go out and can't stand it here. The soup trolley comes into the bay, the HCA asks June if she would like some. June raises her voice: "no" and continues to talk about her mum. The HCA continues talking about soup. June says: "shut up" picks up the [supplement drink], bangs it on the table twice. (June Obs3, Fir, fieldnotes.)

The HCA focussing on hydration at this point seemed to frustrate June further. When Mae was distressed, she had a lot of interactions with staff, but none related to fluid, the nurse reported hydration was:

“Put on the back burner” (Nurse, Fir, Mae, interview.)

The aim became:

“[...] More just calming her down and getting her comfortable [...] trying to get her from a really distressed state to just a little bit more peaceful.” (Nurse, Fir, Mae, Interview.)

This contrasted with the perception of what happens when someone is distressed and delirious according to an Elm nurse:

“Because patients are delirious you end up having to kind of stick with them and [...] they end up quite hydrated because [...] you're offering them tea to calm down, but everyone else [...] ends up missing out.” (Nurse, Elm, Hana, interview.)

Clinical records rarely contained reports on the person's emotional wellbeing. The exception was the activity records within the nursing clinical records which sometimes provided an insight into a person's wellbeing and the HCA's responses:

"Quite tearful in bed, can't remember where she is, cup of tea offered" or "Calm, having her cup of tea" (Kay, Fir, nursing records.)

In these records having a hot drink was often accompanied by the perception of a person's emotional state. The idea that there was a 'therapeutic' value to a hot drink was also noted by several staff:

“She was upset, and [...] it's quite comforting isn't it, to say: 'would you like a cup of tea?' and she said [enthusiastically] 'oh I'd love one', so her tone of voice, it just made it seem like she might enjoy a cup of tea.” (HCA, June, Fir, interview.)

This was also echoed by Mae's relative:

"Mae's relative explained they observed a Consultant on the ward offering her a cup of tea as a therapeutic strategy to try to calm Mae down, the relative said this was helpful "even if the tea doesn't show up" as the words still relax Mae." (Relative, Mae, Fir, notes from a telephone interview.)

OPLWD all spent time looking at the environment around them, their view was often the bed directly in front of them and the wards could be busy and noisy. When personal items were present, such as reading materials, hearing aids, glasses cases, snacks, mobile phones or photographs, they seemed to take on significance to the OPLWD; it was observed they spent time holding, organising, or exploring them. When Gail thought a personal item was missing from her property she became quite fixated on it:

9:58- HCA walks past, Gail: "Hello [...] Where's my glasses?" HCA looks for them but can't find them, [...] HCA: "Maybe you left them at home? Have a look in your handbag." Gail: "Don't be silly, they were here. They were in a case but they're not here now." [...] HCA: "I don't know, I can't see them" and walks away.

10:02- Gail says: "I can't see them" as host walks over. Host asks about tea. Gail says: "I can't see them". The host repeats the question about tea or coffee. Gail: "Coffee please." Host leaves. (Gail, Elm, Obs2.)

Gail remained distressed and focussed on her glasses until her carer arrived, which impeded her from drinking. There were limited opportunities for OPLWD across the wards to interact with anyone beyond the staff providing direct care. Participants were observed to spend long stretches of time alone, not engaging in activity or drifting in and out of sleep, which meant they often missed drinks rounds. The Elm WL seemed to imply that the lack of social engagement may be due to the attitude of staff:

“[...] There are chairs in my bays where the [HCAs] sit watching. I go around and get rid of all the chairs, going: “What are you sitting down [for]? Interact, [...] sit in front of them and try and approach them.” [...] there's no time to sit down on the ward, so I don't expect my special, that I am paying a lot of money for, not to be interacting [...] You know, I don't need a policeman watching people in case they move, to push them back down, I need them to work out what it is that is stopping them drinking or whatever.” (WL, Elm, interview.)

The idea of a policeman is an interesting use of wording, as the HCAs who were providing 1:1 often described their role as offering protection or safety for the OPLWD, rather than engaging the person. Although table 6.6 demonstrates there were few “negative restrictive or negative protective” interactions, these instances were mostly with HCAs, who were the staff interacting most with OPLWD and often related to risk aversion, such as telling the OPLWD to stay seated. This could link with the finding (section 5.3.3) that the staff spending the most time with OPLWD have the least formal knowledge development and training. On two occasions HCAs told the OPLWD that they would spill water jugs if they touched them, which stopped them from using the jug; these interactions were also recorded as negative restrictive. Limited social interaction happened even if the person had a 1:1 with them. OPLWD got few opportunities to maintain their pre-admission hydration skills, unless it was through a functional assessment with the OT, the purpose of which was to assess their discharge requirements. The outcome of this may be a reduction in confidence:

“Since I was ill I don't know if I will still be able to make drinks at home on my own.” (Hana, Elm, interview.)

Lily and Finn also both said they used to make their own drinks at home. Lily seemingly wanted to continue to do this in hospital but was hindered as she did not know how to operate the drinks machine on the ward:

“There are machines but I’m not sure how to use them, I don’t know.” (Lily, Fir, interview.)

One staff member identified it would be useful to have specific activities to engage people:

“To have some sort of activities especially for people who have lost language, [that...] involves [...] non-verbal communication, that could just easily be put out. [...] Because if he gets agitated and all you just keep asking is for him to sit down and there's an empty table in front of him, I mean it's very boring for him [...] (StN, Eddy, Elm, interview.)

Birch was unique as a staff member identified they had a cupboard with a range of activities available. However, this did not mean the contents were used:

“We [...] call it 'the dementia cupboard' [...] it's got [...] some books and puzzles , [...] nail varnish and colouring books [...] And we have sort of those resources, that we probably don't utilise enough to be honest but then again that's due to the nature of the ward and you may have days like today when [...] we have time to do things like that with people. Other days [...] you know we obviously make sure that they're looked after properly and kept dry and fed and watered but there's maybe other things going on, like cardiac arrests” (WL, Birch, interview.)

Activity options are considered a ‘resource’ but are not viewed as related to fundamental care and are placed lower down the hierarchy of tasks. At no time during my observations were activities from the Birch cupboard used. Elm was unique as it had two dining tables, one for women, one for men, but was only used during one observation. The reason it was not used is unclear but could relate to staff feeling people are too unwell or unable to take part:

“It'd be nice if we could sometimes [...] do sitting round the table, with some of them. I don't think I've seen Eddy doing it. I mean at the moment in the

ward that he's in it might not be appropriate. The chap that's opposite him perhaps could do it.” (StN, Eddy, Elm, interview).

Once again, use of the term “nice” indicates that although there is a recognised value in activity and occupation, they are seen as separate or additional extras, not part of providing usual care or the day-to-day functioning of the ward, even when directly associated with fundamental care. When OPLWD used the limited opportunities to interact with other patients, there were barriers to them being meaningful. These challenges may impact on the person’s emotional wellbeing and their comfort in the environment:

12:31: Nurse asks Hana if she would like to sit at the table with the other ladies and she agrees [...] Hana asks another lady if she has any grandchildren, the lady is with a relative who tells Hana on her behalf that the lady has four grandchildren [...] Hana attempts to speak to the other lady and relative [again], but they don’t respond (Hana, Elm, Obs3, fieldnotes.)

The level of impairment, communication difficulties or physical health did not have to be a barrier to finding ways to occupy the person, which was noticeable in the contrast of two observations with Cara comparing a time when she was lying, isolated in pain and following pain relief:

17:27- Cara continues looking distressed [...] she is trying to reposition herself, the nurse walks past and I tell her that Cara has been crying, she says she wants to do the [pain] meds but she also has to greet the new patient [...].

18:06- The nurse attends and says: “I’m so sorry to keep you waiting, I needed to get the [medication] keys from someone” [...] she explains what she is administering, and leaves.

During this time Cara has dinner in front of her but tells the HCA she does not want it, the nurse also comes to check the pain relief is working [...]

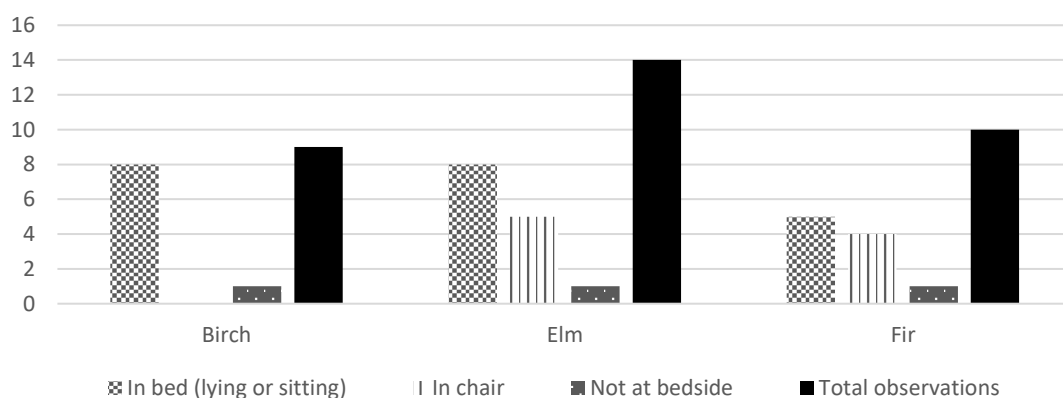
18:27- 18:36 The nurse returns: “Cara you aren’t hungry?” She moves close and Cara opens her eyes wide. The nurse says, (as she repositions Cara’s head and pillow, so she is upright) “I saw you didn’t eat much, do you want some [chocolate] that your [relative] bought?” Cara nods, the nurse opens it and hands her half, “I’ll leave the other half here for you in case you fancy it later” she leaves, Cara eats the chocolate. Shortly after this a host arrives and Cara accepts a cup of tea. She is sitting in bed with a cup of tea, eating a chocolate bar and reading a magazine. (Cara, Birch, Obs2, fieldnotes.)

Cara’s comfort and level of occupation was likely helped by the pain relief, but it was combined with the nurse seeking to find something Cara would enjoy, providing a combination of action, communication and activity to create a social environment which supported her fluid intake.

6.4.2 Physical environment

The physical environment included the ward, but mainly relates to the space around an OPLWD’s bedspace. Participants spent most of their time at the bedside, as shown in figure 6.3.

Figure 6.3 Older people living with dementia participants position at the start of observation



The exception to being at the bedside was the times a person was accompanied on a walk around the ward or if the person’s family arranged to take them to the hospital

café. These infrequent trips were often accompanied by difficulties locating the equipment (a wheelchair) that would enable safety. In one case it was impossible to source a wheelchair, a café trip was abandoned:

10:26am The family want to take Ivan to the café but they need a wheelchair [...], they ask me where to locate one [*I do not know*]. I recommend [...] asking the StN, who says: “there are no wheelchairs.” I ask if the porters will bring one, StN replies: “No I don’t think so, usually people walk.” I ask: “What if they can’t walk?” she says: “ask the HCA.” The HCA says: “someone from the ward would have to get the wheelchair.” I ask how that is organised and she repeats: “Someone will have to go.” I say: “I’ll let his family know.” I do and his relative says: “Not to worry. We just thought we would get him the food he likes and get him off the ward.”

[...]

10:36am The relative reminds the HCA they wanted to take him downstairs and the HCA says they can’t get a chair as they are on a 1:1 and have to stay in the bay, then says: “maybe he doesn’t want to go now as he has a coffee” but the relative replies: “I thought it would do him good.” (Ivan, Obs1, Elm.)

Occasionally, the immediate environment was not conducive to eating or drinking. Once on Birch and once on Elm, male participants’ hospital tables had urine bottles on them, though it was unclear if they were used or empty. On Birch the breakfast was brought by the host and put on the table next to the bottle; four minutes later an HCA removed it. On Elm the urine bottle remained present for the full observation, including while the participant ate breakfast; at one point an HCA moved the bottle when wiping the table but replaced it once the table was wiped. During one observation on Birch Cara had a vomit bowl on her table with a napkin over it, this was removed when lunch was brought around. These instances demonstrate the clinical environment can conflict with creating a pleasant environment for intake and that staff can seem unobservant of the impact these environmental issues may

have, particularly outside of mealtimes. Additionally, these aspects are frequently present on the OPLWD's hospital table.

Staff were observed to make small adjustments to the environment as part of their presence, such as adding their name to the board above the patient's bed to identify themselves. Only two Elm staff members suggested ways the environment could be improved, which may indicate staff do not consider it part of hydration care, or feel they cannot influence it:

“[A] special environment for [OPLWD...with] colour-coded cutlery, [...] or, the surrounding area [...] And you get much more back from them [...]rather] than just like a normal bed in a hospital, if you create a proper environment. [...] it can be unrealistic when you think about costs, but I don't think it's really unrealistic, I think it's more like, willing, to do things.” (Nurse, Eddy, Birch, interview.)

A doctor on Elm felt wall space could be utilised to provide education to families:

“This is an area where a lot of time is spent talking to families about the reasons for decreased oral intake [...] that might be acute medical illness or [...] progression of dementia and, [...] from my experience of dealing with family members, [it's] poorly understood and therefore very emotional and [...] anxiety provoking [...] so I think if there was sort of more publicity, not just about hydration but about oral intake in general [...] developing patient information leaflets and notice boards to talk about, what are the common sense things to do, [...] to try and make that easier for patients and family members to understand.” (Registrar, Elm, interview.)

This section demonstrates there are some barriers to the physical environment supporting hydration care, but there are possible strategies to improve this.

6.5 Summary of communication, action, resources and environmental strategies and barriers to hydration care

The findings presented through this chapter have shown that there are multiple communication, action, resources and environmental strategies which can facilitate hydration care and PCC cannot be separated from these; a table summarising these strategies, with the barriers discussed, are included in appendices 34 - 37.

The strategies were discussed in this chapter separately but need to be combined for successful hydration care. The strategies presented require hospital and ward support for successful implementation. However, an individual staff member's approach can promote aspects of each strategy, particularly communication, action, how resources are used and the way the environment is manipulated to be psychologically and socially supportive. The strategies require staff to work in collaboration with OPLWD and their relatives to provide person-centred hydration care. The findings demonstrate that although there are many strategies for providing person-centred hydration care, there are currently barriers to these strategies being successfully implemented within acute hospital wards. A section will now be presented to discuss reflexivity throughout this thesis.

6.6 Reflexivity

Reflexivity was first introduced in section 4.4. and table 4.3 as being a factor in the approach to rigour. Reflexivity can be defined as: "the practice of critical self-reflection about oneself as a researcher" involving consideration of researcher biases, preconceptions, preferences and the relationship between the researcher and participant (Moorley and Cathala, 2019, p. 11).

Reflexivity has shaped and influenced the whole thesis from conception of the study to, the final writing and presentation of the new knowledge contributed to this area.

Aspects of my previous experience and views of dementia care were discussed in the background, sections 1.3 and 1.4. These sections explained my values as a person and healthcare professional and therefore influenced my views commencing the research journey. Specifically, I explicitly acknowledged my perspective that PCC is synonymous with the way I view dementia and therefore dementia care. PCC is an overt concept within the thesis and explored and justified through chapter three. The view I had of PCC as the optimal approach to care remained constant throughout. However on reflection, my knowledge about facilitating this within an acute hospital has developed further. Considering the findings particularly, and scrutinising how my ideas have developed along the thesis journey, there have been changes in my view of the topic of person-centred hydration care, which are identifiable through documentation in my research diary.

Beginning this study I felt that through undertaking this study I would be able to uncover neat, simple strategies and barriers for individual staff to take on board to improve person-centred hydration care for OPLWD at the point of interaction. Throughout the journey it became clear that research is not neat and clean but messy and tangled, requiring the researcher to move forward and backwards through the data to make sense of the phenomena. I also learnt that individual staff members were part of a complex organisational system and therefore the strategies required for investigating this aspect of care were multifaceted, involving multiple people and they required organisational support and intervention, as well as an individual approach. Other aspects of reflexivity involved my positioning as a researcher and observer, discussed in section 4.7.3.

One perception that was occasionally present but appears less in my research diary - perhaps because I feared documenting it - has changed throughout completing this thesis and I now feel able to discuss it openly. This related to apprehension

about whether the topic was worthy of research. This lack of confidence could have been partly related to imposter syndrome (Clance and Imes, 1978; Gill, 2020), a feeling of inadequacy and therefore an anxiety affecting many early career nurse researchers. I did push the feelings of apprehension away when considering them through the lens of imposter syndrome. However, on reflection the feelings were partly due to the limited prior research about hydration care for older people living with dementia in acute hospitals, which caused me to pause and to question if it was a topic requiring exploration or even if I was missing a body of literature somewhere. Discovering the work of Kitson *et al.* (2019) enabled me to situate this research within an international context, whilst understanding and recognising the importance of research about fundamental aspects of care. Additionally through discussing the topic with peers throughout the research process, and then writing up the findings and recognising the value, all reduced the niggling apprehensions about the topic which were present in the early stages of the thesis.

A final aspect of reflexivity was the emotional strain of witnessing and analysing data where the needs of OPLWD were not always met. This was an uncomfortable position to be in as I was in a role which was observing and not acting to address or rectify these, which was different to any clinical role I have held. This left me in a position of powerlessness, as within my research protocol I knew I had the duty to act if someone was at risk or could be harmed. However, the everyday minutiae of absent interactions or insufficient care, which were not immediately harmful on their own but accumulated over time, amounted to witnessing care which was uncomfortable to see. Sometimes I did not notice the accumulated absence of care during the observation but relived this with new insight through data analysis. My research diary became a strategy to manage and cope with these emotions as well as documenting them, in addition to supervision and allowing myself enough time

to analyse the findings, taking breaks when needed. To ensure I was not responding to the data through an overly emotional state it was important to remember the research topic and questions and display the data that answered these questions, not the data which illustrated my emotional response. This was achieved through awareness and the systematic, rigorous analysis process described in section 4.9. The incorporation of a self-reflective process was an important tool for me to understand my own influence on the analysis of the data and one of the key lessons learnt in this doctoral journey was reflexive governance.

6.7 Chapter summary

This chapter presented the themes and subthemes of strategies for, and barriers to, delivering person-centred hydration care with the acute hospital. These findings answered research question four. These findings were summarised in section 6.5. Following the summary of the findings, section 6.6 discussed reflexivity and how this has influenced the thesis journey from conception to completion. In the next chapter, chapter seven, the findings which answer each research question are discussed in the context of the literature.

7 Discussion

7.1 Introduction

This chapter demonstrates how the findings from chapters five and six provide answers to the research questions. The research questions were developed from the study propositions, in alignment with case study methodology (see table 4.1). Person-centred care (PCC) was the underlying concept utilised in this research, as reflected in the research questions. The findings are discussed through an exploration of the existing literature on the topics of hydration for older people in care settings and PCC for OPLWD in acute hospitals. An extensive search of the literature revealed that the current study is the first study to explore, in-depth, hydration care for older people living with dementia (OPLWD) within an acute hospital and across acute hospital wards. Applying a multiple case-study methodology enabled an exploration of the organisational context, as well as a comparison being made across three wards within one hospital of a multi-site National Health Service (NHS) Trust. The following chapter sequentially discusses the current study's findings for each research question alongside existing literature.

7.2 Research question one: How does the acute hospital affect person-centred hydration for older people living with dementia?

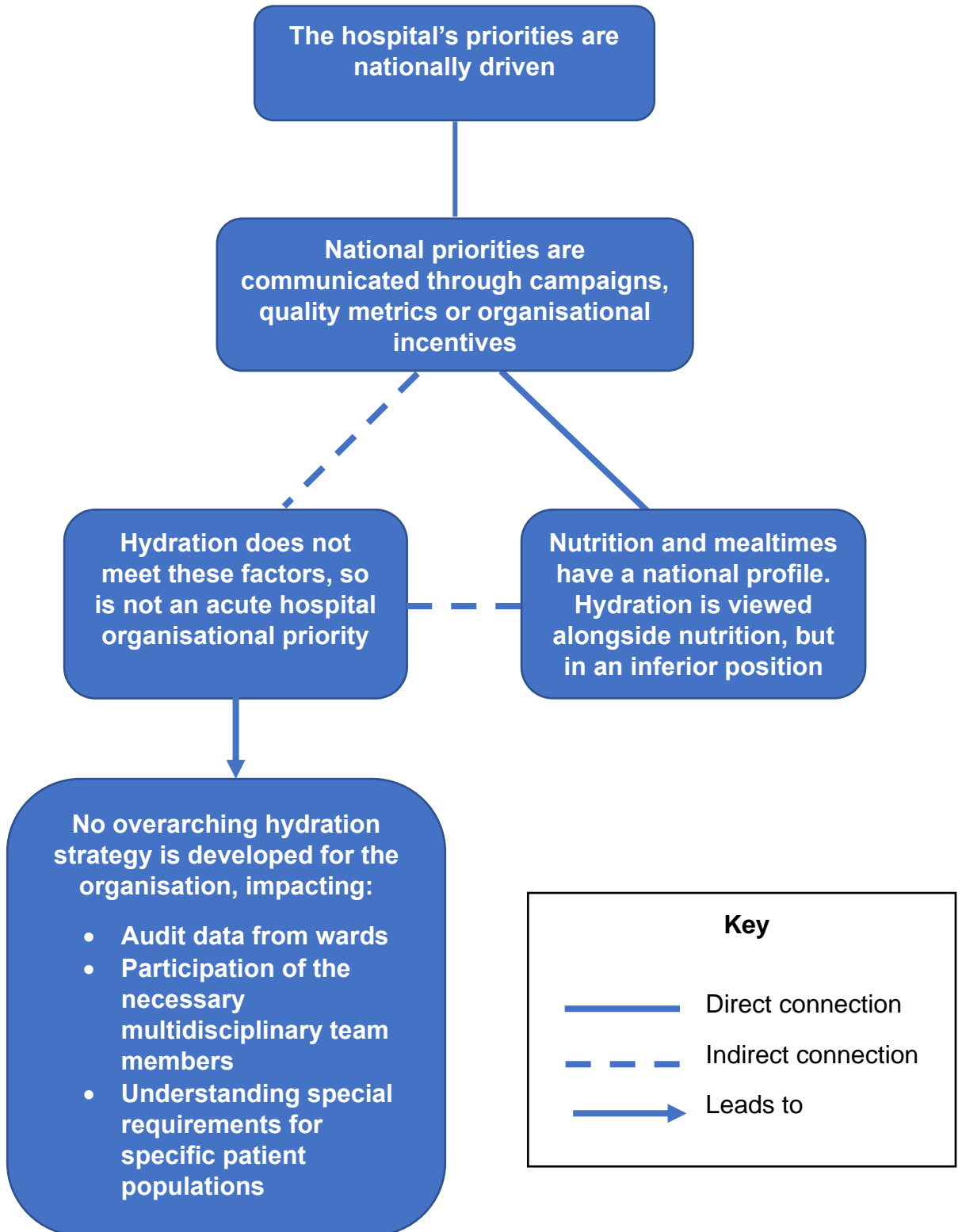
There was one overall theme and two subthemes related to this question, initially presented in section 5.1, table 5.1, and revisited here:

Theme: hydration is an obscured aspect of care

- National drivers: *“National initiatives ... they’re what the organisations really grab.”*
- Dispersed locally: *“We’ve got small strategies going on in different areas”*

Findings chapter five and six answer this question by presenting new knowledge, discovered using a methodology not previously applied to the topic of hydration care for OPLWD within acute hospitals. The findings demonstrated that the provision, delivery, and most hydration-related care for OPLWD were similar across all three wards (the wards are further discussed in section 7.3). A possible explanation for hydration care being similar across the three wards is that the provision of drinks, processes and care were largely influenced by hospital-wide, organisational factors rather than ward-level factors. The findings suggest that organisational priorities were influenced by national, external forces, which at the time of this current study, had not awarded hydration care with a high status. Therefore, areas of care which had a national profile, or were reported on by hospital wards or nationally were prioritised. As a result, hydration care was an obscured area of care in the hospital, removed from national priorities and therefore given limited priority by the hospital organisationally. Figure 7.1 presents a conceptual model developed from the findings from themes one and two, illustrating how this obscurity has developed within the hospital organisation.

Figure 7.1 Exploring how the acute hospital environment impacts on person-centred hydration care for older people living with dementia, resulting in hydration care being an obscured area of care



Organisations and their objectives having an impact on dementia care is in keeping with the existing knowledge about person-centred dementia care in acute hospitals (see section 3.3.1, figure 3.3.) However, the current study explicitly demonstrates, for the first time, that PCC and hydration care are inextricably linked.

The prior hydration literature (see chapter two) alluded to the organisation affecting hydration care through the processes in place to deliver hydration (Godfrey *et al.*, 2012; Lea *et al.*, 2017; Wilson *et al.*, 2020) but an organisational perspective had not directly been sought. The prior literature had collected data from within care settings or dining areas, without exploring the wider context, so the factors which influenced how organisations viewed, decided on and implemented hydration care were not previously revealed. The exception was Cook *et al.* (2019a), who gained an organisational perspective through a survey of care homes, finding most had implemented specific strategies to promote hydration. This current study develops the existing literature about hydration care for older people by seeking data about the acute hospital context. The contextual data demonstrated that the hospital organisation is influenced by national priorities, agendas, and incentives, which exclude hydration, and has led to hydration becoming an obscured aspect of care at an organisational level. The current study's findings revealed no overall organisational strategy and limited policy related to hydration, which in effect meant there was no specific strategy for OPLWD (or other discrete patient groups), further obscuring hydration care for OPLWD. The findings from the current study compared with the findings in Cook *et al.* (2019a) may indicate that some care homes have considered hydration strategies in more depth than the acute hospital. However, due to the survey method used by Cook *et al.* (2019a), the depth and insight into the organisational context is lacking.

The influence of organisational structures on person-centred dementia care supports previous literature, which indicated that delivery of PCC for OPLWD requires support through organisational structures and leadership (Brooke and Ojo, 2018; Brossard Saxell *et al.*, 2019.) The current study's findings demonstrate that organisational objectives limited the ability and drive to provide person-centred hydration care, noticeably through limited hospital policies and strategies, the service delivery, staffing, environmental decisions and available resources. Dewing and Dijk (2016) presented an argument that senior staff in hospitals ignore or underestimate the complexities involved in caring for OPLWD, partly attributing this to national or regional planning. However, it may also be directly related to the motivation and incentive to focus on specific areas of care that result in some other needs of OPLWD becoming obscured.

Additionally, the current study suggests that the ability for staff to shape policies, procedures and practice about hydration care for OPLWD is limited, as the organisation does not collect any audit data or feedback about this from a ward level. Existing literature has indicated that excluding acute hospital staff who care for OPLWD, from influencing policy, procedure and practice, causes feelings of disempowerment (Brooke and Ojo, 2018).

The current study demonstrated how the priorities of the organisation cascaded to ward level and influenced the ward context and culture of care, answering question two, discussed next.

7.3 Research question two: How do ward environments affect person-centred hydration care for OPLWD?

There was one overall theme and four subthemes related to this question, initially presented in section 5.1, table 5.1, and revisited here:

Theme: hydration is overshadowed at ward level and partly obscured from healthcare staff

- Other aspects of care are valued more than hydration: *“I am 1:1...because of the risk of pressure sores”*
- A physical barrier to hydration care for healthcare staff: *“Before ward sisters could get into their own kitchen”*
- Hydration is routinised to an outsourced worker; it is not part of the healthcare staff’s routine: *“When the tea comes you can have one”*
- Views on dehydration: *“Dehydration is not good”*

The ward-level data demonstrated that the acute hospital organisational view of hydration care for OPLWD had cascaded to the wards; hydration was overshadowed at a ward level by other priorities and within wards, hydration care was also obscured from the healthcare staff. This happened in two direct ways. First, the main delivery of hydration was provided by staff who worked for a private company and had no formal healthcare training, situating a crucial part of hydration care, the delivery, away from healthcare staff. Second, healthcare staff were physically excluded from the kitchen, as the kitchen space belonged to the private company. A further reflection of the organisation’s lack of hydration strategy was reflected on the wards which had minimal obvious or reported local hydration strategies or policies. Consequently, hydration lacked prominence at a ward-level, which may further obscure hydration care from healthcare staff’s care priorities.

The views and actions related to hydration care emerged as incongruent. Healthcare staff simultaneously viewed hydration care as ‘basic’ while

acknowledging the risk of dehydration. Despite staff recognising the risk of dehydration, other risks such as falls and pressure ulcers were viewed with more significance, reflecting the organisation's focus. This prioritisation of some elements of care, to the exclusion of other aspects such as hydration, impacts PCC, as all aspects of an OPLWD's physical care and wellbeing require consideration, not just those with organisational value. A conceptual model has been developed to show how these elements relate to question three (see section 7.3, figure 7.2).

The identification of a physical barrier to healthcare staff carrying out hydration care within hospitals is a new addition to the existing knowledge. This may be because limited prior studies explored the full process of hydration care or examined the contextual aspects of hydration care within hospitals. The mode of delivery for drinks was discussed in previous studies and routinised drink rounds were previously identified by authors researching hospital and long-term care settings (Armstrong-Esther *et al.*, 1996; Godfrey *et al.*, 2012; Jimoh *et al.*, 2019; Wilson *et al.*, 2020). In the current study, the private company was found to provide a routinised drink service through regular drinks rounds. Godfrey *et al.* (2012) found at various times, different staff - healthcare assistants, domestics or volunteers - were responsible for the drinks trolley, leading to inconsistencies for older people. In contrast, in the current study, the drink trolley was consistently in the hosts' domain and therefore out of healthcare staff's hands, perhaps because it was a role contracted to a private company. However, the finding within the current study, that drink provision was provided by a private company within a hospital, has not been included in previous hospital hydration literature (Gaff *et al.*, 2015; Godfrey *et al.*, 2012). Whether it is preferable for hosts to consistently provide the drink delivery, or a variety of staff to carry out this duty at different times is unclear, as these two studies were not similar enough to compare the variables, benefits, issues, and problems revealed.

The routinised approach to drinks in the current study was part of the environmental milieu of the ward. Healthcare staff were observed to rely on this round to provide any hot drinks, even when the OPLWD - rarely - requested a drink outside this time and were reluctant to facilitate hot drinks outside of the host's routinised drink round. This has implications for PCC, Brossard Saxell *et al.* (2019) found that being able to adjust ward routines was necessary for facilitating PCC. The physical barrier to hydration delivery that healthcare staff face and the routinised mode of hydration delivery, demonstrates the barriers to providing person-centred hydration care in hospital settings.

At the times healthcare staff offered or prompted OPLWD with a drink it was the one within reach, such as water or a hot drink which had often gone cold. Lea *et al.* (2017) also observed staff offering an OPLWD an available drink, which was not their preference and therefore declined. In the current study, most offers of drinks to OPLWD were made during the drinks rounds and so these were the drinks OPLWD were most likely to drink. These findings reflect those from Gaff *et al.* (2015) that within hospitals more fluids were consumed from the trolley than the jugs on the tables. However, the current study revealed many missed opportunities for a co-ordinated approach between healthcare staff and hosts, resulting in successful hydration care opportunities being missed. This was sometimes due to OPLWD being asleep, or not recognising they were being offered a drink, which supports findings from care homes that drinks rounds benefit independent drinkers and sleeping residents were not woken for drinks (Wilson *et al.*, 2020). The uncoordinated approach between staff reflects how both the siloed nature of roles and the unsocial environment of clinical settings can affect person-centred hydration care. Kitwood (1997) recognised that there needs to be a commitment to creating a team that works together to facilitate PCC. However, in the current study, the

observed care demonstrates that the need for ward staff to build team integration between not only healthcare staff but also service staff, in this case, hosts.

Within the current study, healthcare staff suggested they valued other aspects of physical care more highly than hydration care. The specific care aspects valued varied from ward-to-ward, although they all related to measured areas of care, aligned with a risk-management approach to care or organisational priorities. Similar findings of wards being routinised or task-focussed were identified in PCC literature (Dewing and Dijk, 2016; Digby *et al.*, 2018; Quirke *et al.*, 2019; Reilly and Houghton, 2019; Scerri *et al.*, 2020a, 2020b) and have negative consequences for PCC (see section 3.3.1, figure 3.3). In Godfrey *et al.*, (2012, p. 1204) a hospital healthcare assistant (HCA) explained the facilitation of hydration care via volunteers enabled the HCAs to continue “looking after” the patients, which they expressed would have been prevented if they had to deliver drinks. This points to a disconnection between the HCA’s view of caring and hydration care, their view excludes providing drinks. Separating hydration from other care duties was also found within a care home, staff suggested that forming an additional role to solely provide hydration care would be a solution as they struggled to find the time to assist with hydration care (Mentes *et al.*, 2006). However, more recently, Cook *et al.* (2019) found that care home staff described active hydration care roles, seemingly offering a variety of choices, monitoring for instances where increased hydration was needed, and incorporating hydration into activities and occupation. The previous literature, alongside the current study’s findings, raises questions about whether hydration is viewed as an aspect of care related to health, or viewed separately as a service to be provided and disconnected from healthcare in some hospitals and care homes. Given the fundamental role hydration has in maintaining physical health and wellbeing, the findings pose a new question: how has hydration care in an acute hospital seemingly

fallen into this incongruent position for the care of OPLWD? To explore this question, a closer examination of the roles that individual staff, relatives and OPLWD play could provide further explanations; these are discussed in section 7.3.

Previous literature about PCC within hospitals supports that hospital organisations' prioritisation of performance indicators, safety and routines can impact on PCC through affecting ward cultures (Dewing and Dijk, 2016; Gwernan-Jones *et al.*, 2020; Houghton *et al.*, 2016; Reilly and Houghton, 2019). However, the way physical aspects of care fit into this is more complex. Two papers stated that within the existing culture of hospital wards, physical care and physical needs were prioritised (Dewing and Dijk, 2016; Reilly and Houghton, 2019). However, Houghton *et al.* (2016) presented two conflicting findings: that a focus on safety undermined physical and psychosocial needs of OPLWD but the routinised approach to care led to a focus on their physical care needs. The current study progresses this area of knowledge by unearthing from the data sets that not all physical health needs are equally prioritised, or neglected, by the performance indicators and ward cultures, suggesting aspects of care are viewed in a hierarchical way. This is in keeping with the finding by Jensen *et al.* (2019b) that different aspects of care existed within a hierarchy. Gwernan-Jones *et al.* (2020) found the disease-organising mode of delivering care influenced the perception that OPLWD did not fit into the care provided by the individual wards, which aligns with the finding in the current study that different ward areas valued different aspects of physical care more than others, based on ward speciality; although no ward valued hydration care highly. The findings suggest hydration care is a physical care need which may be undervalued and obscured. It also suggests that when discussing care received by OPLWD within acute hospital research, the term 'physical care' may be too broad a category, as not all 'physical care' has equal status. Therefore, there is merit to researching

physical health needs individually due to the different views within an acute hospital about distinct aspects of physical care. It could be considered that person-centred hydration care is doubly disadvantaged as a care task: alongside the existing challenges of delivering PCC to OPLWD in acute hospitals, hydration care is an aspect of physical care which is not highly prioritised.

Staff in the current study spoke about how dehydration for the OPLWD may impact their own role or tasks completion; hydration was viewed as a way to prevent dehydration becoming an issue for the staff, rather than being linked to well-being of the OPLWD. This finding aligned with studies from long-term care where staff considered dehydration an important health issue and were concerned about connected risks, such as choking, dysphagia, urinary tract infections or renal failure (Armstrong-Esther *et al.*, 1996; Lea *et al.*, 2017; Menten *et al.*, 2006). In contrast, some previous studies found staff viewed hydration as important, and connected this to health, not only risk or ill-health (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Lea *et al.*, 2017), thus demonstrating there is potential to influence staff views on the importance of hydration for health.

7.4 Research question three: How do staff view their roles related to hydration care and how does this compare with observations of hydration care?

These two questions will be answered simultaneously through a discussion about staff roles within the hospital wards. There was one overall theme and four subthemes related to this question, initially presented in section 5.1, Table 5.1, and revisited here:

Theme: Whose role is hydration care?

- Is hydration care everyone's role or no one's role? *"Anybody going past can offer a drink"*
- Training, knowledge and staffing: *"There's a variety of experience and knowledge throughout the MDT"*
- The siloed nature of hydration care roles: a typology

The overarching theme for staff roles was a question about whose role is hydration care? The findings revealed that multiple staff groups within the acute hospital wards had a siloed and compartmentalised role relating to hydration care for OPLWD but staff expressed a view that "anybody" could provide hydration. Further detail of the specific, individual staff hydration roles were presented in the typology of roles (see section 5.4.3, table 5.2).

Staff often expressed the view that hydration care was everyone's role, which contradicted with the observations. Observations indicated staff had individual, mostly unconnected roles which meant effective hydration care was often hindered or neglected altogether. It was unclear who took the responsibility or monitored this aspect of care and the staff roles were found to be siloed. Previous literature had not explicitly examined the distinct roles of a multi-disciplinary team providing hydration care to OPLWD within an acute hospital. Whilst the distinct roles all have potential value in providing person-centred hydration care, an observation was that they were not sufficiently connected to ensure adequate hydration care was provided consistently. One potential explanation for this relates to the discussion in 7.2; that there is a lack of focus on this area of care within policy and monitoring, thus influencing the acute hospital and ward contexts, and the necessary organisational structures to carry out this area of care are not provided. Alternatively,

these siloed roles may be reflective of many aspects of physical care within an acute hospital and the current study of hydration care for OPLWD illuminates this issue, which may not only be unique to hydration care.

Whilst other literature did not explicitly explore the range of roles linked to hydration care, aspects of staff roles can be inferred. Lea *et al.* (2017, p. 5175) used similar phraseology to the current study, describing the occurrence of “professional siloing” in the care home setting. Though this was described as existing alongside hierarchies that prevented change from occurring because the hierarchies impacted communication about specific areas of care. The current study’s findings illuminated how siloed roles affect direct person-centred hydration care. There were barriers identified to the hospital leadership being able to hear the views of ward staff about person-centred hydration care, which likely affected their ability to change hydration care. However, this was only inferred through contextual information and documents, rather than discussed by the ward staff, so it was a less clear finding in the current study. Within this study the siloed roles seemed to impact communication between staff; the ability to communicate, co-operate and share knowledge amongst a professional team has been deemed necessary to facilitate PCC, so the siloed roles are likely to create barriers in achieving this (Brossard Saxell *et al.*, 2019).

As discussed in section 7.2, in the current study, the hosts always delivered the drinks during the drinks rounds, contrasting with data from Godfrey *et al.* (2012) who found delivery varied across several staff groups and this impacted care. As such, the current study’s findings about roles involved in hydration care may not be generalisable across all acute hospital settings where roles could vary. Therefore, researchers investigating hydration within acute hospitals should collect data on the

mode of hydration delivery and consider specific staff roles when designing methodology and reporting hydration care research.

The current study found nurses did facilitate hydration care, but this was almost always aligned with providing medication, which was the primary goal during the interaction (discussed in section 5.4.3.2). Previous literature has also linked medication administration with the opportunity for hydration care (Godfrey *et al.*, 2012; Jimoh *et al.*, 2019); the current study provides further evidence that this is a key time for promoting hydration care as it is the principal time nurses promote hydration. This finding has important implications for clinical care, as nurses should maximise this opportunity if they are working with OPLWD, who are at risk of low fluid intake.

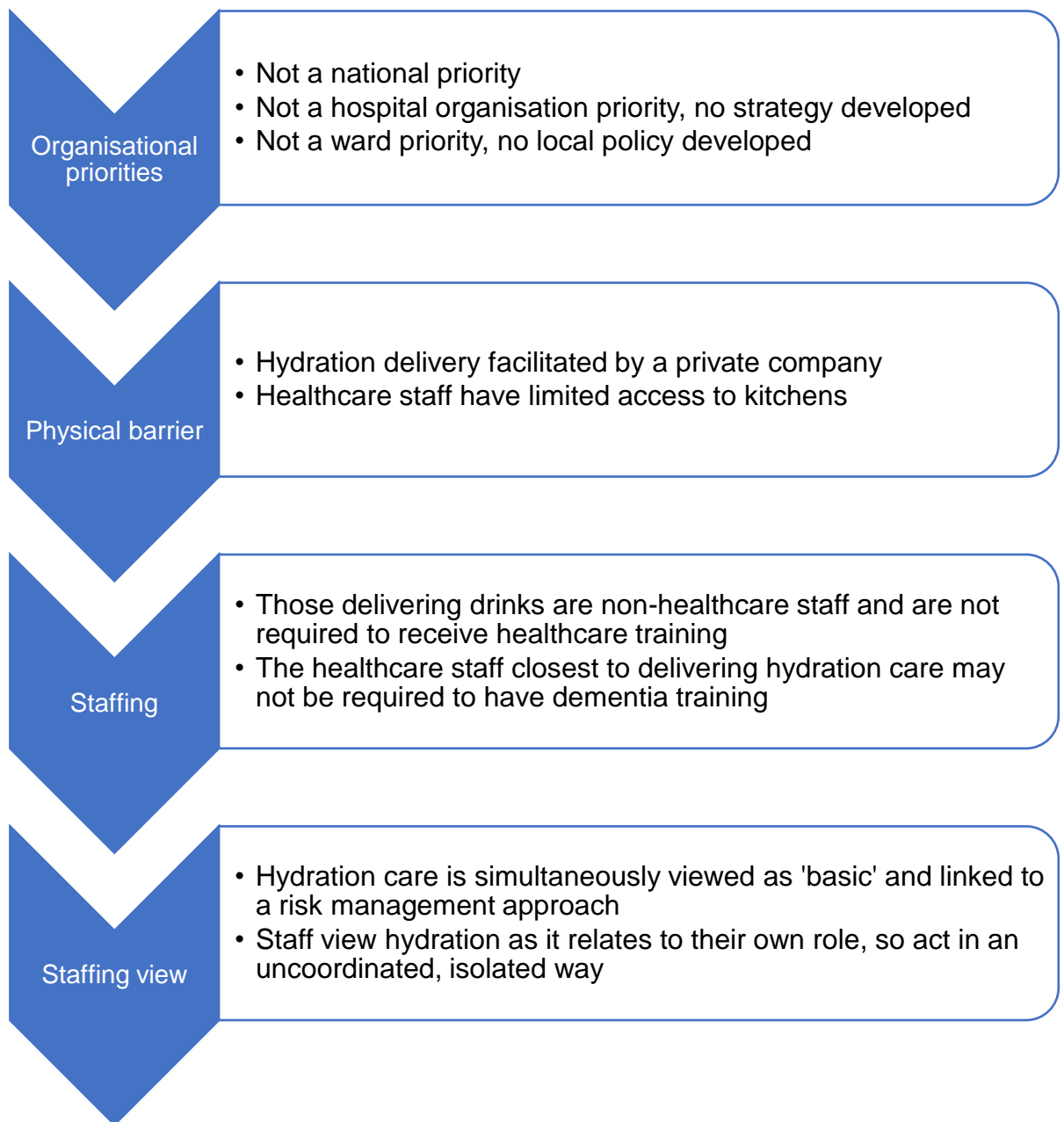
Another factor found to influence person-centred hydration care on the wards within the current study was that staff members have various knowledge and skills relating to hydration care. Staff providing the direct hydration care had the least amount of training or knowledge development, as identified in section 5.4.2. There was no evidence that ward staff of any level, other than doctors, had formal workplace training or education about hydration and hydration was not a topic covered in the hospital dementia training. Only one previous study collected data about staff training, also finding there was no hydration-related training, but training was provided about risk factors such as dysphagia (Beattie *et al.*, 2014a). It can be concluded that the hospital and other care environments may not consider hydration, or hydration for PLWD, a topic which requires formal knowledge development or education in practice. Previous studies evidenced that healthcare professionals, PLWD and their relatives consider theoretical and practical knowledge about dementia care an important requirement of providing suitable acute hospital care (Brooke and Ojo, 2018), so a lack of formal knowledge

development about hydration care for OPLWD could potentially have negative implications for care and satisfaction.

In summary, staff view hydration care as everyone's role, however, the findings demonstrate that hydration roles are siloed, with limited opportunities for collaboration, which creates a broken chain for successful, person-centred hydration care. In contrast to hydration care being everyone's role, the ownership of hydration care is disjointed and there is a risk that person-centred hydration care becomes no-one's role. This is impacted by further as there is a variety of knowledge amongst staff members, with limited formal knowledge development about hydration or dementia care provided to the staff who deliver the majority of hydration care.

Figure 7.2 has been created to illustrate how hydration care remains obscured from the healthcare staff on the wards and reveals the ways that the acute ward environment and staff roles impact hydration and related care for OPLWD.

Figure 7.2: An explanation of how the acute hospital context impacts hydration care for older people living with dementia, resulting in hydration care being obscured from healthcare staff



This concludes this section which has demonstrated the influence the acute hospital and ward environment has on person-centred hydration care and associated staff roles, the direct hydration care provided to OPLWD and strategies and barriers to delivering this in a person-centred way are presented in the next section.

7.5 Research question four: Using the concept of PCC how can hydration care for OPLWD in acute hospital wards be facilitated and what are the barriers?

This question was answered through the findings presented in chapter six, which identified the strategies and barriers to delivering person-centred hydration care on the wards. There were four themes and 12 subthemes related to this question, initially presented in section 6.1, table 6.1, and revisited here:

Theme: Communication

- Communication between staff and OPLWD
- Communication between staff
- Communication between staff and relatives

Theme: Action

- Providing direct support with hydration care for OPLWD
- Leadership
- Associated areas of care

Theme: Resources

- Identifying OPLWD
- A documentation system to record information about the OPLWD
- Identifying people who require additional help with eating and drinking
- Choices and availability

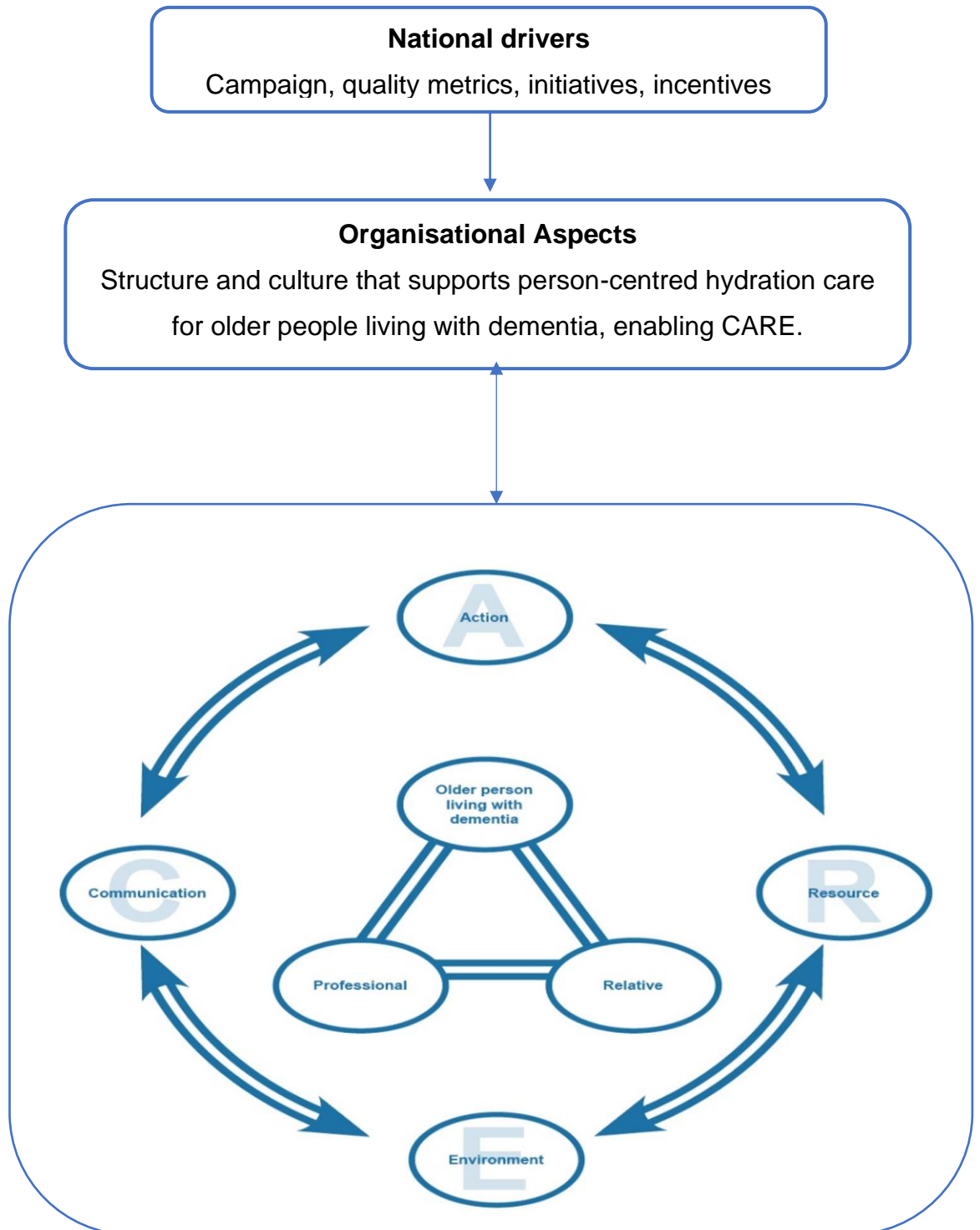
Theme: Environmental aspects

- Social environment
- Physical environment

A model was developed to display the factors which were found to be necessary to facilitate person-centred hydration care, using the acronym CARE: communication, action, resources, and environmental aspects. These aspects need to be situated within a supportive organisational context, which considers the necessity of

including the triangle of care: the staff, the OPLWD and their relatives. Figure 7.3 has been developed to illustrate this finding.

Figure 7.3 A model to demonstrate how person-centred hydration care can be facilitated for older people living with dementia in acute hospitals



These aspects of care delivery, which are necessary for person-centred hydration care will now be discussed. The four elements of CARE will be discussed separately, although they complement each other.

7.5.1 Communication

To facilitate person-centred hydration care, communication was required between staff and OPLWD, between members of staff, and between staff and relatives. These aspects aligned with the principle of the triangle of care, which was presented in section 3.2.6 and reflected in the findings of both chapter five and chapter six. Communication between the and within the triangle of care is discussed in sections 7.4.1 - 7.4.4.

7.5.1.1 Communication between staff and OPLWD

Communication between staff and OPLWD is essential to the person-centred delivery of hydration care. The hydration literature reported some of the ways communication was a strategy or barrier to hydration care and the PCC literature supports the importance of communication. However, the current study has added to the existing knowledge by providing communication strategies which can facilitate person-centred hydration care, also revealing current barriers (see appendix 34)

Communication is necessary to understand the individual barriers to hydration care expressed by OPLWD, such as pain or fears of incontinence. Based on the approach to communication identified, which was task-focussed and short in length, the perspectives of OPLWD are at risk of being overlooked, or OPLWD are not given time to communicate their needs. These hospital setting findings align with those from a recent care home-based study, where there was limited opportunity for older people to make an autonomous choice about their drinks (Wilson *et al.*, 2020). The current study demonstrates that OPLWD did express insights about why their intake

was reduced during interactions, but these were not always noted by staff. This issue was compounded by the reliance on verbal communication, overlooking non-verbal communication, and the siloed nature of staff roles. The perspectives expressed by OPLWD in this study are reflective of previous studies which found the process of drinking was viewed as a burden by some older people who may be concerned about incontinence (Godfrey *et al.*, 2012; Wilson *et al.*, 2020). The way that the task-focussed process of drink delivery minimised communication supports the findings of Godfrey *et al.* (2012) who reported social interactions were missed during drink facilitation. The current study raises the importance of skilled communication alongside providing hydration care, to enable staff to acknowledge and respond to the individual views expressed by OPLWD, that may give insight into potential individual barriers to hydration care.

Communication is considered important within the PCC literature also, and is jeopardised by care delivered in a task-oriented way with psychosocial aspects of care being seen as a luxury (Houghton *et al.*, 2016). The current study demonstrates that the sometimes-overlooked views of OPLWD could provide beneficial insight into aspects of the care tasks being delivered and can be part of the strategy for facilitating the task.

When communication strategies were delivered successfully, presented in section 6.1.1, these created a connection between the staff member and the OPLWD while aligning interactions with hydration. Similarly, Ullrich and McCutcheon (2008, p. 2913) say staff were helping the OPLWD “to connect with the reality of fluid intake” which they also found was a strategy for hydration care.

7.5.1.2 Communication between staff

The current study's methodology had not included a focus on collecting data about the communication between staff, including any verbal handovers or discussions away from the bedside. However, aspects were uncovered through the data collected, showing that communication between staff affects hydration care, and the current communication between staff was a potential barrier to person-centred hydration care for OPLWD.

Staff communication data were also collected through clinical documentation analysis, a dissonance was found in the current study, where the healthcare assistants (HCAs) spent the most time with the OPLWD and the hosts delivered hydration most regularly, but neither staff group documented these areas of care in the care records, thus creating a dissonance between the provision of hydration care and the documentation and monitoring of hydration care. A similar segregation was found in Ullrich and McCutcheon's (2008) care home research: they identified nurses produced and updated the written care plans but did not carry out the most care, illuminating a dissonance between those determining care plans, and those delivering care.

Fluid balance charts, used for documenting a person's fluid intake, were used across all the wards in the current study. According to these charts, many of the OPLWD had oral fluid intakes which were lower than the recommended standard, but this was not regularly noted in the multidisciplinary team (MDT) clinical records where individual assessments and care plans were documented. The records from fluid balance charts cannot conclude that all OPLWD had intakes which were too low, as fluid balance charts were viewed as imprecise by staff in this study (see section 6.1.2). In addition, the staff delivering, supporting and monitoring drinks were not the staff documenting the drinks and the delegation of who was responsible for

the associated tasks in the current study was unclear. These findings support previous studies where staff or researchers have questioned the accuracy of fluid balance charts (Armstrong-Esther *et al.*, 1996; Godfrey *et al.*, 2012; Wilson *et al.*, 2020).

Yet, it could still be that the OPLWD in this study had fluid intake below the recommended intake, alongside an inaccurate fluid balance chart recording. Observations during the current study revealed that OPLWD drank little fluid spontaneously and many opportunities to encourage fluid intake were missed. This is in keeping with existing literature which indicates that older people in care settings often have fluid intake which is below the recommended standards (Armstrong-Esther *et al.*, 1996; Gaff *et al.*, 2015; Gaspar, 1999; Jimoh *et al.*, 2019; Spangler and Chidester, 1998). The current study, alongside the existing literature, supports a view that OPLWD in care settings, including hospitals, are at risk of having insufficient hydration; additionally, the strategies to monitor intake in hospital are deemed inaccurate and consequently inadequately measure the risk.

Through analysis of MDT and nursing clinical records, which had not been included in previous research about hydration care for OPLWD in acute hospitals, the current study adds to the knowledge about hydration care for OPLWD. The findings show that documentation about hydration care for OPLWD among acute medical teams and trauma and orthopaedic teams is often overlooked within MDT documentation, though less so with elderly medical teams. Across all the ward specialisms nursing entries regarding hydration were found to be frequent but lacking in details or information about a person's individual needs or intake, nor did they provide care plans or references to the fluid balance chart.

7.5.1.3 Communication between staff and relatives

The OPLWD within this study had relatives who visited them while they were in hospital, which provided an opportunity to observe the interactions between relatives and staff. These observational data were supported by relatives and staff interviews, which included discussions about their interactions with each other. Whilst staff frequently identified that relatives could be sources of information about an OPLWD, improving their ability to care, this was not always carried through to staff-relative interactions. An interesting incidental finding was that when relatives were present, staff often interacted even less with the OPLWD and infrequently initiated interaction with the relative. This observation was supported by Daisy's relative (see section 6.1.3) who was concerned this meant Daisy was missing out on care whilst they were present. Some staff viewed relatives as having specific functions in the environment, such as providing choices which were not available, supporting when the OPLWD was distressed and assisting with care tasks. However, it was unclear if they had communicated these expectations to the relatives directly; one staff member expressed frustration recounting when relatives had not helped support drinking. Similarly, care home staff expressed frustration about the level of support provided by relatives when they considered it lacking (Mentes *et al.*, 2006). Prior literature has indicated that care related to nutrition and hydration can be emotive for relatives (Bernoth *et al.*, 2014); the current study's findings indicate that there is potential for hydration care to be emotive for healthcare staff also. Tensions between staff and relatives have been noted in previous literature about dementia care within hospitals and the findings are that they could have been prevented through enhanced communication (Dewing and Dijk, 2016).

Relatives relied on staff to give them information about their family member's care and at times felt they had not received this information when it was related to

hydration care, as discussed in section 6.1.3. This may indicate that the communication for a reciprocal relationship between staff and carers requires further development within the acute hospital setting. Similarly, Houghton *et al.* (2016) suggested that a strategy for family involvement is often not clear or not present within the acute hospital. Carers' involvement has been noted as being important for the psychosocial wellbeing of OPLWD (Houghton *et al.*, 2016; Reilly and Houghton, 2019). The current study illustrated that OPLWD were more likely to drink when their carer was present, so it can be considered carers' presence is beneficial for biopsychosocial wellbeing.

7.5.2 Action

Many of the OPLWD would have benefited from assistance with hydration care, which was not always provided. Successful actions mostly happened alongside communication strategies. Actions included setting up the environment, preparing the OPLWD, providing direct support, or facilitating hydration alongside other care tasks to promote hydration care. However, as identified in section 7.3, there were times when the siloed roles did not link sufficiently to achieve successful hydration care.

The OPLWD in the current study all required support with hydration care at times, which aligns with the findings discussed in chapter three. Staff expressed in interviews that they assisted with hydration care but the observations revealed that the actions offered often came at times which were disconnected from the moments of hydration delivery, resulting in missed opportunities for hydration care. Ullrich and McCutcheon (2008) identified that most care home participants received touch interventions such as hand-over-hand, touching the person's hand or wiping away spillages; in contrast, most observed actions in the current study related to placing or passing drinks. Ullrich and McCutcheon's (2008) participants may have required

more support than the participants in the hospital, as they found all the participants in their study required continuous assistance. However, as there was no standardised tool used in the current study or Ullrich and McCutcheon's (2008) study to determine the level of assistance an OPLWD required with hydration, is it not possible to provide a view on differences in each participant's level of need.

The current study's finding that the delivery of drinks did not always link up with the required actions to support the OPLWD to drink was not discussed in other studies and this may be unique to the hospital setting. However, other studies (Godfrey *et al.*, 2012; Menten *et al.*, 2006) suggested that the ability to provide hydration care was often limited by time constraints or other care tasks being prioritised, so aligning the active support with drink delivery may have happened in other research but not reported.

7.5.3 Resources

In the current study there were resources available to promote person-centred hydration care but they were infrequently available, utilised or promoted. The resources included ways to identify OPLWD, people who required extra support with food and drink, and a way to document personal information, including the preferences of the OPLWD. Resources also included the choices or drinks or types of cups available. There was a disparity between what drinks were available and what was offered. Staffing issues such as skill mix, knowledge development and training are also relevant resources, these were discussed in section 7.3

To provide PCC it is necessary to gain information about the OPLWD (Brooker and Latham, 2016; Brossard Saxell *et al.*, 2019), as the current study found a lack of evidence that information was collected or documented about OPLWD or their hydration needs, this raises questions about whether the care provided on the wards

was person-centred. In the current study staff said they found out information about OPLWD through their interactions with them as well as via their families. This strategy aligns with research that suggests nurses form a holistic picture of an OPLWD through a combination of communication and interpretation; observing signals and communicating with relatives and colleagues (Brossard Saxell *et al.*, 2019). However, from the observational data in the current study, staff were observed working with the OPLWD for the first time and, overall, the instances of staff attempting to gain information about a person were limited and there was evidence that some key information was not known about a person's physical needs and preferences even where relatives said they had shared it, as indicated in section 6.3.2.

Gwernan-Jones *et al.* (2020) identified that staff need skill and experience to be able to elicit the information required to interpret cues from OPLWD and develop a holistic view of their care. The current study's findings identified that those providing the most hydration care are those with the least formal training and knowledge. Therefore, the omission of documented information about a person's needs may also place an unnecessary burden on these staff members, who potentially do not have the underpinning knowledge to interpret the cues provided by OPLWD. In the current study the hospital did provide ways to document personal information about a person (see section 6.3.2) but the documentation was rarely used.

Beverage and cup choices on the wards in the current study were limited, there was a sense that staff accepted this was just the way it was, uninfluenceable, or they felt that relatives could provide items to make up for any deficiencies. In the current study there was no acknowledgement by staff through observation or interviews that OPLWD may desire a particular cup, although relatives and OPLWD confirmed they had preferences for cup types and beverages. This aligns with previous research

which demonstrated older people express personal preferences for specific cups and types, timings and temperature of drinks (Cook *et al.*, 2019a; Godfrey *et al.*, 2012; Jimoh *et al.*, 2019; Wilson *et al.*, 2020). At times in the current study, OPLWD's preferences were either not asked, such as for Finn who expressed that he preferred milk but he had not been asked his preference (see section 6.3.4), or mistaken as in the case of Daisy who told staff she wanted tea but her relative later clarified she meant coffee (see section 6.3.2). These instances highlight that it is important to find out a person's preference from them as soon as possible and to check with their relatives if possible. As most participants in the current study did not have their preferences documented it was not always possible to tell if the drink that they were offered was in keeping with their usual preferences but based on the interviews and observations, it would seem this was variable. Previous studies have also found that older people do not always get offered drinks which are their preferences (Lea *et al.*, 2017; Wilson and Dewing, 2020).

7.5.4 Environmental aspects

The current study revealed that OPLWD spent most of their time in bed or occasionally sitting in a chair beside their bed. This resulted in isolation and periods of boredom or where the OPLWD were sleeping throughout the day. The physical and social environment provided limited opportunities for OPLWD to be included in the tasks which happen around them or be involved in social interactions. This situation regularly affected the ability for OPLWD to experience person-centred hydration care. Despite environmental constraints, individual staff could influence the environment to promote person-centred hydration care, but this relied on an individual staff member breaking from the usual care trajectory and did not commonly occur. Efforts to maintain a social, supportive environment with purposeful activity could positively influence hydration care. Additionally, when

individual staff limited attempts by OPLWD or other staff to alter the environment the OPLWD could become further withdrawn, distressed, or frustrated and then attempts to provide hydration care became challenged. Staff expressed that offering a hot drink was a way to influence the social environment and to provide reassurance or comfort, however, from my observations once someone was highly distressed, they did not accept that drink in that moment.

The current study supports previous literature that identified how the hospital physical and social environment can be unfamiliar, restrictive, disrupt a person's normal routine and contribute to negative emotions for an OPLWD (Dewing and Dijk, 2016; Digby *et al.*, 2018; Houghton *et al.*, 2016; Reilly and Houghton, 2019; Scerri *et al.*, 2020b). These previous studies demonstrate the link between the environment and psychosocial wellbeing, whereas through exploring hydration care, the current study demonstrates the link between the environment, psychosocial and physical wellbeing. These findings support the view of PCC advocated by Kitwood (1997), that the mind cannot be divided from the body and physical needs must be met alongside psychological needs to promote wellbeing. The current study develops this prior knowledge by providing evidence about how environmental factors influence person-centred hydration care.

Within the previous literature there was a suggestion that within long-term care settings, OPLWD in their own rooms may consume less than in communal or dining areas (Reed *et al.*, 2005; Wilson *et al.*, 2020). However, whether communal opportunities to drink would improve hydration within the hospital is unclear as there was only one occasion when this was observed. Additionally, as all the immediate environments that OPLWD occupied across the three wards were uniform, there were no comparators to assess if differences promoted or hindered hydration care. This area may be beneficial for future research.

7.6 Chapter summary

This chapter discussed the findings in the context of the research questions and within the context of previous research, with explanatory figures to illustrate the themes and related concepts. The findings demonstrate that person-centred hydration care for OPLWD in an acute hospital is not consistently achieved and illuminated the organisational and ward-level barriers and the strategies that could improve this area of care.

Section 7.1 provided an answer to research question one, demonstrating that hydration is an area of care which is obscured at an organisational level. Other areas of care are prioritised. These priorities can be nationally derived through campaigns, finances or metrics. As hydration does not have a national profile and is viewed as linked to, but inferior, to nutrition, it is further obscured. There are limited ways for the organisation to gain information about hydration care from a ward level. This is new knowledge, as organisational aspects of hydration care had not previously been reported through research.

Section 7.2 provided the answer to research question two, suggesting that the wards reflect the acute hospital organisation priorities, so hydration is also obscured at a ward level, particularly for healthcare staff. The reflection of organisational priorities at a ward level results in staff focussing on other areas of care more than hydration. An added barrier to hydration at a ward level is the physical barrier created by routine, drink delivery being outsourced to a non-healthcare staff member and the kitchen not being accessible to healthcare staff.

Section 7.3 provided answers to research question three through posing the question: whose role is hydration? This question was required as there was a contrast between the staff view that 'anybody' could provide hydration care and the

observation that it was unclear who held the onus to provide hydration care. This was illustrated by revisiting the findings from the typology of staff roles (see section 5.4.3, table 5.2) that staff held siloed roles, which were not sufficiently linked to ensure successful person-centred hydration care was provided for OPLWD. This was further complicated by a variety of skills and knowledge amongst staff members, with the staff providing the drinks or the most care to OPLWD with the least amount or no formal healthcare training.

Section 7.4 answered research question four by providing a model to demonstrate how person-centred hydration care can be achieved in acute hospitals, although there are currently barriers to attaining this. The triangle of care - staff, OPLWD and relatives - was revisited, with the finding that around this triangle communication, action, resources and environmental strategies were required to provide successful person-centred hydration care. This would necessitate support from the organisation, which is influenced by national drivers.

The next chapter summarises the key contributions to new knowledge. Additionally, the study's strengths, limitations and recommendations for clinical practice, research, policy and education are presented, followed by the plans for dissemination and the conclusion to the thesis.

8 Conclusion

The previous chapter demonstrated how the findings answered the research questions, discussing these in the context of previous research. In this final chapter, the contributions to new knowledge will be clarified. The strengths and limitations of the research will be presented and recommendations for future practice, research, education, and policy will be made. The plans for dissemination will also be explained.

Through an exploration of hydration care for older people living with dementia (OPLWD) in acute hospitals this study has progressed previous research by demonstrating that there are challenges to both person-centred care (PCC) and hydration care at an organisational and ward level within acute hospital wards, which impacts hospital staff ability to deliver person-centred hydration care for OPLWD. Currently, person-centred hydration care is not consistently achieved within an acute hospital setting for OPLWD. Despite this, individual staff can still achieve aspects of person-centred hydration care, but this is going beyond the current way of working and does not align with usual care in the acute hospital ward. It can be concluded that, for person-centred hydration care for OPLWD to be consistently achievable in acute hospitals, changes are required at a national, organisational, ward and individual staff level.

8.1 Contributions to new knowledge

The thesis has used an original approach: multiple-case study methodology and the concept of PCC to explore the topic of hydration care for OPLWD in acute hospitals. This approach provided a range of new knowledge with relevance to practice, research, education, and policy.

The original contributions to new knowledge are now presented.

- At hospital organisational level the priorities for care are seemingly determined by national, external forces which are measured with data collected from wards; this situation has obscured hydration care as this has not been included in national considerations which are measured.
- Ward-level care reflects the priorities of the organisation, therefore hydration care is obscured from healthcare staff on wards, as staff priorities align with the organisational priorities and the specialism of the ward. Dehydration is viewed as a risk, as opposed to hydration being a component of wellbeing.
- Hydration care is carried out by a multitude of staff; it is simultaneously viewed as a routinised service and part of healthcare.
- The various roles involved in hydration care for OPLWD in acute hospitals have been collated into a typology, which demonstrates the roles are siloed. Due to the siloed nature of individual roles, they often do not link together to facilitate the communication, action, resources and environmental approaches required to provide successful hydration care for OPLWD; as a result, person-centred hydration care is rarely achieved within the wards.
- A model for considering the organisational, ward and individual level barriers and strategies to delivering person-centred hydration care was developed (figure 7.3). The model of hydration CARE explains that for person-centred hydration care within an acute hospital, specific Communication, Action, Resources and Environmental considerations must be fostered around the triangle of care (staff, OPLWD and their relatives). This needs to be supported by the organisation, and the organisation is influenced by a national agenda.

8.2 Strengths

A literature review demonstrated that this is the first study which used a multiple-case study approach, with a range of data collection methods to investigate hydration care for OPLWD and included patients, relatives, and multi-disciplinary staff team at ward and hospital-wide level.

The benefits of a case study were the use of multiple data collection methods and sources, which allowed the complexities of hydration care for OPLWD to be explored at a contextual level, as well as ward level. Multiple data collection methods allowed for data triangulation and the ability to consider in depth the range of influences on hydration care within the acute hospital: the national policies, the local policies and documents, the clinical documents, the staffing, the OPLWD and their relatives.

The case study used multiple cases which enabled comparison across three wards (the cases), which revealed that the organisational context had a large influence on the ability to deliver person-centred hydration care, surpassing any ward-level differences.

The case study also used multiple units of analysis, enabling in depth exploration of the care for 13 OPLWD, thus yielding a greater understanding of the PCC needs of multiple individuals with dementia. The use of predominantly qualitative methods enabled an in-depth exploration of the phenomenon of interest, which was an area that previously had little empirical research. The integration of quantitative observational data to support the qualitative findings strengthened the study.

The findings have relevance to all acute hospital settings where OPLWD are likely to be admitted. The use of PCC as an explicit concept, discussed in a dedicated chapter (chapter three), places the research design and findings within a current,

understandable context that is aligned with the recommended practice for dementia care. This overt framework, which is internationally recognisable, supports the transferability and use of the findings beyond the hospital that the research was conducted within, enabling a framework of reference, and understanding for multiple healthcare disciplines, beyond the region and country that the research was conducted within. The multiple data sources and approach to analysis ensured a transparent data trail, which adds credibility to the study.

8.3 Limitations

Conducting a case study in one hospital was a practical consideration necessary for the constraints of a doctoral research project with data collected by one researcher. One acute hospital does limit the generalisability for other hospitals. However, a general - but not identifiable - description of the hospital and a rich contextual description provides the ability to compare similarities with other hospitals. However, as discussed in the strengths, the data were also strengthened by comparison across three wards and the use of an overt concept: PCC.

An exploration about the service-model of hydration delivery at an organisational and ward level was not built into the methodology. The findings demonstrated that the specific service model for hydration, which in this study was facilitated through an outsourced contract to a private company, had implications for hydration care within the hospital. This had not been considered during the research design stage, or during the choice of hospital to conduct the research within. This may limit the findings when compared to hospitals with different service models for hydration care. Additionally, the hospital-wide contextual interviews focussed on staff who held a healthcare professional role, not a service-orientated role, as the focus of the study was on care. However, identifying that this service model impacted on direct

hydration care was an important contribution to the hydration literature and is something future researchers will benefit from considering in their research designs; it would also merit further exploration.

The research was designed to gain an understanding of the care received by OPLWD, therefore, observations took place which observed direct care and the interviews were conducted with staff who had interacted with the OPLWD who were participants. The findings suggested there may be additional staff communication about the OPLWD's hydration care away from the bay where the bed was situated and therefore not observed. Future research may benefit from capturing data from these verbal interactions, which may be further understood through observing verbal handovers and any relevant multidisciplinary team meetings. Additionally, within this research design, the research interviews were weighted towards staff who had most contact with the OPLWD. Further opportunity to explore staff perspectives may have been gained from ward-level interviews with staff who had less contact, or no contact with OPLWD during the observations, such as the inclusion of dieticians and additional doctors.

There was a practical challenge, due to personal circumstances, where there was an extended period between data collection and data analysis, which had implications for familiarity with the data. Negative consequences were minimised by using a research diary during data collection which I was able to revisit during the data analysis stage and by dedicating a significant amount of time to data emersion through extended submersion in the data and relistening to all the recorded interviews and reading all the transcripts to refamiliarise myself as part of the analysis protocol.

8.4 Recommendations for research, practice, education, and policy

As this research was situated in the clinical setting, there are many recommendations for practice, see table 8.1, however, there are also recommendations for research, education and policy which will benefit hydration care for OPLWD admitted to acute hospitals.

8.4.1 Recommendations for practice

The recommendations for practice are at three levels: organisation, ward and individual staff. The recommendations are displayed in table 8.1.

Table 8.1 Organisational, ward and individual practitioner recommendations for practice

| Practice area | Recommendations |
|---------------------|--|
| Organisation | <p>To promote hydration care as a fundamental area of practice which is valued through:</p> <ul style="list-style-type: none"> • Development of a hydration strategy which includes consideration for patient populations that may be at additional risk for experiencing issues related to hydration care within hospitals (i.e. for OPLWD). • Set up a multidisciplinary, hospital wide group which considers hydration care within the organisation and across wards. • Show an organisational commitment to understanding and improving hydration care through facilitating data collection and/or feedback about hydration care from ward staff, patients, and relatives. • Consider hydration care as a multidisciplinary aspect of care, which requires understanding and co-ordination across all staffing groups. • Ensure all staff groups (healthcare and non-healthcare) have the knowledge, skills, and development opportunities to understand their hydration responsibilities and can undertake these in the ward settings; this could be achieved through development of a knowledge skills framework for hydration care and including this as a topic at induction. • Include hydration as a topic within dementia training, to highlight this is an area of care that OPLWD are likely to require a person-centred approach to care which has biopsychosocial implications. |

| Practice area | Recommendations |
|---------------------------------------|--|
| <p>Ward</p> | <p>To develop and maintain a co-ordinated team approach to hydration care for OPLWD by:</p> <ul style="list-style-type: none"> • Promoting hydration care as a valued fundamental aspect of care • Developing a local strategy for hydration care for OPLWD, which ensures each staff member knows their responsibility for hydration care set up, delivery, monitoring and escalating concerns. • Considering that all OPLWD are at risk of experiencing some difficulties with hydration care, and they would benefit from a person-centred approach. • Including relatives for OPLWD in discussions and practical steps about hydration care. <p>Provide the resources to facilitate person-centred hydration care, ensure they are available, and that everyone knows how to access them; the recommended resources to consider are:</p> <ul style="list-style-type: none"> • A way to identify people living with dementia (or with a cognitive impairment) on the ward. • A system to identify which patients require support with drinking, and clear delegation of staff who will provide this support. • A care plan for hydration that can be shared with staff, the OPLWD and their relatives. • A written and pictorial drinks menu with the choice of drinks and cups (and any aids) which are available, to complement written and pictorial food menus. • A system for all members of the multidisciplinary team to be able to be able to identify which patients have a fluid balance chart in use. • A co-ordinated approach to collecting fluid balance information, e.g. ensuring the staff member giving out drinks know who to report to if a person declines a drink or where to record this. • A document to record information about an OPLWD, their needs and preferences which is accessible for new patients and their relatives when they arrive on the ward and once filled out is visible for all staff who are working with the OPLWD. <p>Promote a social and physical environment that:</p> <ul style="list-style-type: none"> • Enables, supports, and encourages communication between staff and OPLWD. • Enables, supports, and encourages communication amongst staff teams. • Enables, supports, and encourages communication between staff and OPLWD's relatives. • Ensures physical access to hydration for OPLWD, their relatives and staff. |
| <p>Individual practitioner</p> | <p>To utilise communication, action, the available resources and influence the social and physical environment to include healthcare and non-healthcare staff, OPLWD and their relatives to achieve person-centred hydration care.</p> |

8.4.2 Recommendations for research

The topic of hydration care for OPLWD was identified as an important area for research by OPLWD and their relatives (Alzheimer's Society, 2013); the current study has contributed to this area. Throughout this study, further areas for research have been identified which would build on the current study's findings. Beneficial areas for future research to consider and develop understanding concern:

- How staff communicate between themselves about hydration care for OPLWD.
- The different models for the delivery of hydration services within hospitals and any impact these have on hydration care for OPLWD.
- Further exploration of staff roles and perspectives about hydration for OPLWD, particularly roles which are less visible in the direct care such as dieticians and doctors.
- Implementation and evaluation of the person-centred hydration CARE strategies developed and recommended through this research.

8.4.3 Recommendations for education

This research has demonstrated that hydration care is a complex area of care. Through healthcare training and education, hydration care should be reframed away from being a 'basic' care task, which it is not. Framing hydration care as a valued, fundamental care need is better suited to studying this aspect of care.

This research has also demonstrated that OPLWD have specific hydration needs within an acute hospital ward and this should be reflected through dementia education and training, to contribute to the progression of PCC which considers the biopsychosocial needs of OPLWD.

8.4.4 Recommendations for policy

Policy should promote a national agenda to improve the understanding and delivery of hydration care on acute hospital wards as a fundamental care need for OPLWD.

Potential ways this can be achieved are through:

- Development of a national campaign.
- Providing financial incentives to collect data about and improve hydration care.
- Collecting and reporting hydration related quality metrics.
- Funding research streams about hydration care for OPLWD.
- Publishing guidelines about hydration care for OPLWD in collaboration with multiple staff groups and with patient and public involvement.

8.5 Plans for dissemination

As described in section 8.4 this research will be of interest for those within practice, education, and policy; sharing research findings requires dissemination.

Dissemination has commenced through sharing progress of the study and initial findings within the university through poster presentations at university-wide doctoral summer school and within the school of health and social care doctoral support group.

Wider dissemination of the literature reviews and study findings are planned through publications in relevant academic journals, and professional journals for the practical recommendations for healthcare.

Contact will also be made with the Alzheimer's Society which was involved at the patient and participant involvement stage, to ascertain any networks which would be interested in the study findings.

At a practice level I plan to share the findings with the hospital the research was conducted in, as well as the hospital I am currently practising in. This will be through nursing and research forums. As a specialist clinician with a role in older people's healthcare within acute practice, I will utilise study findings in training sessions that I have input into and in my clinical work.

For wider reach, I plan to submit abstracts to healthcare clinical and research conferences.

8.6 Conclusion

This research succeeded in the aim to use the concept of PCC to explore and describe the factors influencing hydration care and the associated experiences of OPLWD in acute hospital wards. This adds to the knowledge of person-centred and fundamental care for OPLWD within acute hospitals.

Literature related to hydration for older people in care settings was explored through chapter two. This chapter provided an understanding of what is already known in this area, this highlighted that although a person-centred approach was recommended, this concept had not featured within the existing literature about hydration care for older people in care settings.

The concept of person-centred care was consolidated through chapter three which explored and defined the concept of PCC for PLWD and examined the literature which places the theory within the acute hospital, the setting relevant to this research. Chapter two and three contributed to the creation of the research questions and lay the foundations for designing the methodological approach.

The study demonstrated that hydration care for OPLWD in acute hospitals is a complex activity involving the multidisciplinary healthcare and non-healthcare team.

The complexities of person-centred hydration care for OPLWD are not prioritised at an organisational level, which results in this being obscured at a ward-level. There are ways that person-centred hydration care is achieved at an individual staff level, but there is no consistency in how hydration care for OPLWD is approached, meaning currently, person-centred hydration care is rarely achieved within acute hospital wards. To improve the biopsychosocial health and wellbeing of OPLWD, acute hospital organisations should commit to improving the person-centred delivery of hydration care, by applying the recommendations made as a result of this research.

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Appendices

Appendix 1: Table of literature reviews related to hydration for older people or older people living with dementia

| Reference | Setting, participants and number of articles included | No of articles included, year range of articles included and type of studies | Aim | Findings (Hydration intake related) | Recommendations for future research | Other |
|---|---|--|--|---|--|---|
| (Hodgkinson <i>et al.</i>, 2003) | People over 60 years old. In acute care, residential care or community setting. | Studies/ articles (n=17) Years: 1966-2002 Quantitative studies | To identify risk factors for dehydration in older adults. To identify strategies to assess the risk and strategies increase oral fluid intake. | Fluid intake was not increased whether the position of the feeder was sitting or standing. Offering fluids every 1.5 hours to bed-bound residents increased fluid intake compared to three-hourly checks with no prompting. | No recommendations made | |
| (Bunn <i>et al.</i>, 2015) | People over 65 years old Living in long-term care settings | Studies (n=23) Articles (n=33) Years: Quantitative studies | To assess interventions and environmental strategies to increase fluid intake or reduce dehydration risk. | Most studies included had a risk of bias. 6 out of 9 studies demonstrated an increase in fluid intake using multicomponent strategies such as: increased choice and availability of drinks, staff awareness and assistance with drinking and toileting. High-contrast cups was also reported to increase fluid intake for men with Alzheimer’s disease. There were inconclusive changes to environmental modifications of the dining room, advice to residents, display of drinks, and the way thickened drinks were delivered. | Recommendations for further research at resident, institutional and policy level. The authors recommend high-powered RCTs that use valid outcome measures, to reduce bias. | The authors highlight there were a lack of interventions to identify and assist with barriers at a personal level, which they find concerning as it is not in keeping with person-centred care. |

| Reference | Setting, participants and number of articles included | No of articles included, year range of articles included and type of studies | Aim | Findings (Hydration intake related) | Recommendations for future research | Other |
|----------------------------------|---|--|--|--|---|--|
| (Abdelhamid et al., 2016) | <p>People living with dementia or mild cognitive impairment.</p> <p>Studies from any setting.</p> | <p>Interventions (n=43)</p> <p>Years:1992-2012</p> <p>Quantitative studies</p> | <p>To assess the effectiveness of direct interventions to support food and drink intake for people with dementia.</p> | <p>There were no promising interventions identified that improved hydration.</p> <p>The review stated that there was not enough evidence to suggest any intervention as effective or ineffective.</p> <p>Studies with social interventions suggested the possibility of improving quality of life, although they were small.</p> | <p>Interventions require further research for PLWD in different settings and at different stages of dementia, using high quality randomised controlled trials. Research should consider social support around food and drink, including the improvements this may have on quality of life</p> | <p>Most studies reported on nutritional intake, or mealtimes.</p> |
| (Bunn et al., 2016) | <p>People living with dementia or mild cognitive impairment.</p> <p>Studies from any setting</p> | <p>Interventions (n=56)</p> <p>Studies (n= 51)</p> <p>Years: 1995-2013</p> <p>Quantitative</p> | <p>To assess the effectiveness of indirect interventions to support food and drink intake for people with dementia</p> | <p>Most studies had a high risk of bias, with small numbers of participants.</p> <p>There were no promising interventions identified that improved hydration. One study reported increased fluid intake for men with Alzheimer's disease with high contrast cups.</p> | <p>There are gaps in the research related to interventions to support drinking and fluid intake. Further research is required to investigate interventions to support drinking.</p> | <p>1 study out of 51 from a hospital.</p> <p>Most studies reported nutritional intake.</p> |

| Reference | Setting, participants and number of articles included | No of articles included, year range of articles included and type of studies | Aim | Findings (Hydration intake related) | Recommendations for future research | Other |
|--------------------------------|---|--|---|--|---|---|
| (Oates and Price, 2017) | Adults In hospital or care home setting. | Studies: Articles: (n=23) Year of studies: 1984- 2015 | To identify clinical assessment tools which find patients at risk of low fluid intake. Assess the impact of interventions to promote drinking. | Results suggest people with a cognitive impairment are at risk of low intake and responded to strategies to increase drinking. Regular prompts to drink increased intake in care homes residents in three studies, particularly those with cognitive impairment in one study. A 'hands-free' or sports bottle (Depending on level of independence) reduced length of stay, dehydration and infection. Documentation was also improved and no statistical analysis was performed. One study of 76 employees found that less than half regularly reported fluid intake and only 15% demonstrated accurate knowledge of fluid requirements. A survey of 53 lead nurses found that only 45% had a policy to monitor hydration, 15% felt the policy was not up-to-date and 11% did not have a policy. Challenges communicated were completing documentation, keeping practice up-to-date and staff awareness | The authors suggest interventions to increase fluid intake should use modifiable factors such as a beverage cart to prompt or receive drinks. | The review title and aim suggests it is a review about care for 'older patients,' however the search was for articles including any aged adult. |

| Reference | Setting, participants and number of articles included | No of articles included, year range of articles included and type of studies | Aim | Findings (Hydration intake related) | Recommendations for future research | Other |
|------------------------------|---|--|---|---|--|--|
| (Cook <i>et al.</i> , 2019b) | Older adults. Residential and nursing home setting. | Studies (n=3) Search from 2013-2019 Quantitative and mixed methods | To update the search carried out by (Bunn <i>et al.</i> , 2015) and identify further hydration interventions. | The evidence for hydration interventions is not strong. Studies suggest the use of multi-component interventions are most successful to optimise hydration. There is still debate about what adequate oral fluid intake for an individual is. The competency of the workforce to deliver hydration care is gaining attention. Hydration care research should be a priority- focus is often on dysphagia or nutrition. | Research is required to: <ul style="list-style-type: none"> • understand intake requirements for older adults, as well as the ways to increase intake. • understand the link between hydration strategies and health outcomes. The contribution of relatives should be considered in future research. Workforce issues need to be considered, including staff competence and abilities to provide person-centred approaches to hydration care. | The authors warn that the implementation of strategies to support hydration care within care homes will be complicated by potential low levels of recruitment, retention, high staff turnover and issues with accessing skill development. |

| Reference | Setting, participants and number of articles included | No of articles included, year range of articles included and type of studies | Aim | Findings (Hydration intake related) | Recommendations for future research | Other |
|----------------------------------|--|--|---|--|---|--|
| (Wilson and Dewing, 2020) | People living with dementia and older people. Location not specified | Studies (n=) Search from 2001- 2018. Qualitative and quantitative | To identify strategies to prevent and manage dehydration for older people or people living with dementia. | The findings suggest that a person-centred approach is required to promote hydration to people living with dementia. The strategies identified fit into the following categories: <ul style="list-style-type: none"> • Physical and social environment. • Staff communication strategies • Access to drinks • Drinking vessels • Individual preferences | Research is required to understand the barriers to providing optimal hydration, including the barriers experienced by healthcare staff when providing hydration care or communication between staff members. Strategies should be cost-effective, feasible and apply to all settings. | The authors identify a lack of research explaining why dehydration remains prevalent and what prevents staff from implementing strategies. |

Appendix 2: Data extraction tool for integrative literature review

Date of extraction:

Study details:

| | |
|--------------------------------------|--|
| Lead author | |
| Year | |
| Country (ies) | |
| Does it meet the inclusion criteria? | |

Type of study:

Qualitative

Quantitative

Mixed methods

Location

Number of locations:

Sample size and description:

Methodology:

Data collection tools and methods used:

Findings:

Recommendations:

Strengths:

Weaknesses:

Comments:

Appendix 3: Ratings of the hydration literature review articles using MMAT

Screening questions (for all qualitative, quantitative and/or mixed method articles)

S1- Are there clear research questions?

S2- Do the collected data allow to address the research questions?

| Quantitative articles and relevant MMAT questions | | | | | | | | | |
|---|--|----|----|-----|-----|-----|-----|-----|---|
| Article number | Authors | S1 | S2 | 4.1 | 4.2 | 4.3 | 4.4 | 4.5 | Comments |
| 1 | (Armstrong-Esther <i>et al.</i> , 1996) | Y | Y | Y | Y | Y | CT | Y | Unclear how many were eligible for the inclusion |
| 2 | (Beattie <i>et al.</i> , 2014a) | Y | Y | Y | Y | Y | N | Y | |
| 3 | (Chidester and Spangler, 1997) | Y | Y | Y | N | Y | Y | Y | Excluded people with acute illness |
| 4 | (Gaff <i>et al.</i> , 2015) | Y | Y | Y | Y | Y | Y | Y | |
| 5 | (Gaspar, 1999) | Y | Y | Y | Y | Y | Y | Y | |
| 6 | (Jimoh <i>et al.</i> , 2019) | Y | Y | Y | Y | Y | Y | Y | |
| 7 | (Namasivayam-MacDonald <i>et al.</i> , 2018) | Y | Y | Y | N | Y | Y | Y | Strict exclusion criteria, some |
| 8 | (Reed <i>et al.</i> , 2005) | Y | Y | Y | Y | Y | CT | Y | |
| 9 | (Spangler and Chidester, 1998) | Y | Y | Y | N | Y | Y | Y | Does not state how they were recruited. Detailed analysis in article 3. |

Question 4: Quantitative descriptive questions

4.1 Is the sampling strategy relevant to the address the research question?

4.2 Is the sample representative of the target population?

4.3 Are the measurements appropriate?

4.4 Is the risk of nonresponse bias low?

4.5 Is the statistical analysis appropriate to answer the research question?

| Mixed methods articles and relevant MMAT questions | | | | | | | | | | | | | | | | | | | |
|--|--------------------------------|----------------|----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|---|
| Article number | Authors | S ₁ | S2 | 1.1 | 1.2 | 1.3 | 1.4 | 1.5 | 4.1 | 4.2 | 4.3 | 4.4 | 4.5 | 5.1 | 5.2 | 5.3 | 5.4 | 5.5 | Comments |
| 10 | (Cook <i>et al.</i> , 2019a) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Surveys informed interviews |
| 11 | (Mentes, 2006b) | Y | Y | Y | Y | CT | CT | CT | Y | Y | Y | Y | Y | Y | Y | CT | CT | CT | No Data analysis of interviews described. Interview content unclear |
| 12 | (Ullrich and McCutcheon, 2008) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | |
| 13 | (Wilson <i>et al.</i> , 2020) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | |

Question 1: Qualitative

- 1.1 Is the qualitative approach appropriate to answer the research question?
- 1.2 Are the qualitative data collection methods adequate to address the research question?
- 1.3 Are the findings adequately derived from the data?
- 1.4 Is the interpretation of results sufficiently substantiated by data?
- 1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?

Question 4: Quantitative descriptive questions

- 4.1 Is the sampling strategy relevant to the address the research question?
- 4.2 Is the sample representative of the target population?
- 4.3 Is the risk of nonresponse bias low?
- 4.5 Is the statistical analysis appropriate to answer the research question?

Question 5: Mixed methods

- 5.1 Is there an adequate rationale for using a mixed methods design to address the research question?
- 5.2 Are the different components of the study effectively integrated to answer the research question?
- 5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?
- 5.4 Are the divergences and inconsistencies of quantitative and qualitative results adequately addressed?
- 5.5 Do the different components of the study adhere to the quality criteria of each tradition of the methods involved

| Qualitative articles and relevant MMAT questions | | | | | | | | | |
|--|--------------------------------|----|----|-----|-----|-----|-----|-----|----------|
| Article number | Authors | S1 | S2 | 1.1 | 1.2 | 1.3 | 1.4 | 1.5 | Comments |
| 14 | (Bernoth <i>et al.</i> , 2014) | Y | Y | Y | Y | Y | Y | Y | |
| 15 | (Godfrey <i>et al.</i> , 2012) | Y | Y | Y | Y | Y | Y | Y | |
| 16 | (Lea <i>et al.</i> , 2017) | Y | Y | Y | Y | Y | Y | Y | |
| 17 | (Lea <i>et al.</i> , 2019) | Y | Y | Y | Y | Y | Y | Y | |
| 18 | (Mentes <i>et al.</i> , 2006) | Y | Y | Y | Y | Y | Y | Y | |

Question 1: Qualitative

- 1.1 Is the qualitative approach appropriate to answer the research question?
- 1.2 Are the qualitative data collection methods adequate to address the research question?
- 1.3 Are the findings adequately derived from the data?
- 1.4 Is the interpretation of results sufficiently substantiated by data?
- 1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?

Appendix 4: JBI data extraction form

(The Joanna Briggs Institute, 2014, p. 34)

Appendix 3

JBI Data Extraction Form for Review for Systematic Reviews and Research Syntheses

| | |
|--|--|
| Study Details | |
| Author/year | |
| objectives | |
| Participants (characteristics/ total number) | |
| Setting/context | |
| Description of Interventions/ phenomena of interest | |
| Search Details | |
| Sources searched | |
| Range (years) of included studies | |
| Number of studies included / | |
| Types of studies included | |
| Country of origin of included studies | |
| Appraisal | |
| Appraisal instruments used | |
| Appraisal rating | |
| Analysis | |
| Method of analysis | |
| Outcome assessed | |
| Results/Findings | |
| Significance/direction | |
| Heterogeneity | |
| Comments | |

Appendix 5: The results of the appraisal for person-centred care review articles

| Authors | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | Comments |
|--|---|---|---|---|---|---|---|---|---|----|----|---|
| (Gwernan-Jones <i>et al.</i> , 2020) | Y | Y | Y | Y | Y | Y | Y | Y | U | Y | Y | |
| (Reilly and Houghton, 2019) | Y | Y | Y | Y | Y | Y | Y | Y | U | Y | Y | |
| (Brossard Saxell <i>et al.</i> , 2019) | Y | Y | Y | Y | Y | Y | Y | Y | U | Y | Y | |
| (Houghton <i>et al.</i> , 2016) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | |
| (Dewing and Dijk, 2016) | U | Y | Y | Y | N | N | U | Y | U | Y | Y | |
| (Brooke and Ojo, 2018) | Y | U | Y | Y | U | U | Y | Y | U | Y | Y | Research aim is different in abstract and main body |

Y=Yes, N=No, U=Unclear

Critical appraisal checklist questions

1. Is the review question or aim explicitly stated?
2. Were the inclusion criteria appropriate for the review question?
3. Was the search strategy appropriate?
4. Were the sources and resources used to search for studies appropriate?
5. Were the criteria for appraising studies appropriate?
6. Was critical appraisal conducted by two or more reviewers independently?
7. Were the methods used to minimise error in data extraction explicitly stated?
8. Were the methods used to combine studies appropriate?
9. Was the likelihood of publication bias assessed?
10. Were the recommendations supported by the reported data?
11. Were recommendations for policy and/or practice supported by the reported data?
12. Were the specific directives for new research appropriate?

Appendix 6: Table of review findings and description

| Paper | Finding | Illustration/ Example |
|--|---|--|
| (Gwernan-Jones <i>et al.</i> , 2020) Hospital Staff (1) | Hospitals can improve staff experiences of caring for people living with dementia by fostering person-centred care | Conceptual map in article. Staff wanted to provide PCC. Institutional and ward level factors prevented them from doing this, which impacted on job satisfaction. When they were able to satisfaction was higher. Hospitals could improve staff experience by promoting PCC. |
| | Person-centred care aligned with staff perceptions of 'good care.' | 'good care' according to staff provided for the emotional and physical needs of PLWD (p. 6). Interactions between PLWD and staff "occur along a continuum" "from care focussed on tasks/ routines and physical care to care that involves personal interaction that supports personhood alongside physical care" (p.8) |
| | Staff were prevented from providing person-centred care | There were barriers to providing 'good' care. |
| | 1d Inadequate levels of training. | When staff had more experience, they were able to recognise responsive behaviour as unmet need, otherwise behaviours could be misinterpreted as neurological impairment (p.9) When staff lacked experience, they "try to fit [PLWD] into the 'medical' or 'nursing' model" (p.9) Knowledge and skills gaps were compounded if there was poor staff role modelling (p.9) |
| | Performance indicators and ward cultures that prioritised care needs. | Routines based on efficiency of physical care staffs could be a barrier to PCC- even for staff with more experience (p.9) There was a perception care for PLWD took more time, and staff felt they should spend more time on other patients, as physical health was prioritised. (p.9) Staff had different approaches to carers. There was a recognition it was beneficial to involve them, but ward policy/ strategies were not clear (p.9) |

| | | |
|---|---|--|
| | Ward cultures that inhibited the sharing of knowledge across roles and hierarchies, including lack of documentation about personal aspects of PLWD. | Hierarchical issues meant that staff who had the most information about the PLWD did not always feel empowered to utilise this information (across and within roles) (p.10) Systems to access information about the Plwd were not consistently utilised or were difficult to access. Staff had to re-establish information from shift-to-shift. (p.10) |
| | Physical environments that prevented familiarisation, social interaction and occupation. | There was a perception that the busy environment was not suitable for Plwd (p. 10). Environments were set up to promote physical health, not interaction. In one study with a more 'homely' environment- the change of environment was not enough to foster homeliness, interactions that promoted feelings of safety were also required (p. 10) |
| | The ability of hospital staff to deliver person-centred care was linked to job satisfaction | The values of staff connected to their job satisfaction, if they could meet care that matched their valued, they felt satisfied, if not they did not feel satisfied. (p.10) |
| | Conflicts in care. | Conflicts in care resulted from staff not being able to provide the care they wanted to, which led to negative feelings (p.11) The care for Plwd was complex and was not reflected in staff: patient ratios, there was a conflict to provide "physical care (cure)" or "emotional care (care." (p. 11) "an implicit and often unacknowledged conflict between opposing discourses, one around the nature of medical care, and the other around the nature of PCC" (p.11) |
| | Coping with emotions. | The emotional burden could be relieved by creating barriers and physically withdrawing from the Plwd or disengaging- which could be achieved by focussing on tasks (p.11-12) "deaden one's conscious" (p.11) To protect emotions staff could "embrace the personhood of the Plwd, protect themselves without jeopardising the personhood or suspending the personhood of the Plwd" (p.12) They may vent to other colleagues or take the problems home. |
| | Job satisfaction. | PCC supported job satisfaction, but staff felt they were made to focus on routine or task-focussed care, not supporting psychological wellbeing (p.12) |
| (Reilly and Houghton, 2019) Patients (2) | Values | Organisational and environmental factors that hinder the needs of Plwd. (p.84) |

| | | |
|--|---------------------------------|--|
| | Infrastructures | Physical environments and clinical structures hindered Plwd, “the place, pace and space” were unsuitable (p.84). Multiple demands on staff could prevent Plwd receiving physical care, especially if they required assistance (p.84). This could also impact psychological needs. Patients reported confusion from the noise. The periods of inaction contributed to withdrawn behaviour. (p.84) |
| | Systems of care | The wards were based on the medical model- this led to task-driven care. (p.84). Routines with little interactions with Plwd could damage dignity (p.84) or restraint was observed. |
| | Individualised | Care practices could hinder or facilitate the abilities, capacity, personality and preferences of the Plwd. (p.86) |
| | Not caring for the “person” | Plwd felt unsure what was happening, rushed, excluded from decisions, fearful about discharge. (pg. 86) Paternalistic and prescriptive language was noted (pg. 86) Plwd who were more independent were seen more positively, Plwd with additional needs were referred to by their needs (p.86). |
| | Caring for the “person” | Some staff did have person-centred attitudes (p.86) Care could be communicated to suit the needs to the PLWD or distraction used to provide care or alleviate boredom (p.86) Identity could be preserved through interactions. (p.86) Task-based approaches, around physical care could be prioritised (p.86). |
| | Perspective | The perspective of the Plwd and how they engaged with the acute care environment. (p.86) |
| | Disruption and coping | The normal routine was disrupted by a hospital admission which could lead to Plwd becoming distressed, attempting to occupy themselves by gathering belonging or becoming disengaged, or worry about their family (p.86) The environment could exacerbate confusion or expressions of discomfort and disorientation (p.87) |
| | Perceived level of independence | The hospital impacted on the independence of Plwd. The shared toilets, lack of control of lighting, noise and space were all problematic. Walkways were cluttered meaning it was hard for Plwd to find their way. Boredom was frequent and linked to lack of stimulation and personal space (p.87) |
| | Social Psychological | How social ambience enabled the Plwd to feel socially confident. |

| | | |
|---|--|--|
| | Socialising with confidence and autonomy | Social interactions and relationship building were ways Plwd attempted to assert independence. Psychological supports included choices in care, meaningful relationships with staff and social inclusion (p.87) Plwd often voices that being in hospital was a negative experience exacerbated through lack of autonomy, paternalistic climate and constraints around freedom and choice. (p.87) |
| | External supports | Relative visits were important for mental and social wellbeing. Family involvement benefited care as they could communicate the needs and wishes of the Plwd and make sure their needs were heard. Plwd appreciated their opinions being heard in the studies (p.87) |
| (Brossard Saxell <i>et al.</i> , 2019) Nurse experience of facilitators to PCC (4) | Internal Facilitators | |
| | Experiences and Knowledge | Knowledge and experience benefited the ability of nurses to provide care as they had more strategies to use to engage the Plwd and better ability to interpret patient's needs (p.12) Theoretical knowledge of dementia and education were of benefit (p.12) |
| | Values and beliefs | Nurses' values and beliefs motivated the way they carried out care. (p.12) PCC approach was important to see the person behind the disease (p.13) This all contributed to establishing rapport (p.13) |
| | Professional identity | Professional identity contributed to PCC (p.13) They felt their profession was well placed to voice the person's needs, participate in interdisciplinary cooperation and if others were not providing it, to ensure patients received PCC (p.13) |
| | Empathy | Being empathetic ran alongside the will to provide the best possible care (p.13) Nurses may have attempted to view the experience of hospital from the perspective of the Plwd and adapted their care accordingly (p.13) This merged the professional and personal self, allowing emotional involvement with the Plwd, which led to nurses compensating for aspects of the persons care which diminished their personhood (p.14) |
| | External Facilitators | |
| | Physical environment | Creating a home-like physical environment with colour, photos was felt to contribute to the social environment. (p.14) Maintaining a hazard free, calm environment enabled Plwd greater freedom (p.14), as was placing Plwd in rooms close to the nursing station. Open bays were felt to promote socialising between patients (p.14) |

| | | |
|---------------------------------|--------------------------------------|--|
| | Organisational Culture and Structure | A collaborative environment between professions benefited PCC and increased nursing knowledge and abilities for reflection. (p.14) PCC increased when nurses could prioritise this type of care above other tasks. (p.14) Support from other nurse of nurse specialists could benefit nurse development (p.15) Leaders that were involved and valued PCC were beneficial, as was organisational aspects such as allocating time for nurse-patient interactions (p.15) |
| | Facilitating actions | |
| | Forming a Holistic picture | PCC was a journey that sought to gain a holistic picture of the person, gathered through a variety of communication and interpretation methods. (p.15) Communication could be non-verbal through physical and behavioural signs (p.15) Gaining life stories contributed to PCC (p.15) |
| | Establishing Trust | Delivering PCC required a trusting relationship to be established between the nurse and the Plwd (p.16) Trust could be built through being receptive to the PLWD's communication needs, choosing words carefully, confirming emotions, engaging socially, distraction, non-verbal communication and body language- and adapting to the situation (p.16) |
| | Adjusting routines and interventions | Adapting from task-orientated routines and standardised care plans enabled PCC to be delivered (p.16-17) Some nurses felt ward routines gave them a sense of control that aided care delivery. (17) Families could be asked to help with Plwd if staff could not find the time to be with them (p.17) "using creativity to continually customise the delivery of care interventions" (p.17) Personal items could be used to reduce distress (p.17) |
| (Houghton <i>et al.</i> , 2016) | Valuing | Focusses on infrastructure and management. |
| Staff experience (5) | Pathways of care | Providing the specialist care Plwd require is challenging in the acute setting (p.111) Plwd may be moved frequently during hospital admissions impacting on orientation and delirium (p.111) Discharge could be prolonged, resulting in a perception that Plwd were "bed blocking" (p.111) |
| | Culture of care | Individual and organisational philosophies impacted on the care received (pg.111) Staff attitudes varied between finding care for Plwd mundane or rewarding. A focus on safety left psychosocial or physical aspects of care deprioritised (p.111) Lack of confidence meant staff focussed on physical aspects of care (p.111) |

| | | |
|--|--|--|
| | | <p>“specialling” and restraint were used, sometimes inappropriately and with minimum consideration to engaging the person. (pg. 111)</p> <p>Stereotyping of Plwd was found (p 111)</p> <p>There was differences in knowledge between HCAs and other members of the team, lack of understanding impacted on care (p.112)</p> |
| | Individualised | Supporting individualised, person-centred care |
| | “pieces of the puzzle” | <p>Knowing the person and having ‘the pieces of the puzzle’ helped with understanding their behaviour and could aid appropriate care (p.112)</p> <p>PCC was understood differently by senior staff and staff providing direct care (p 112)</p> <p>When staff knew more about the person, they could promote autonomy and independence. (p.112)</p> <p>Signs, photos and clocks aided the environment but there was conflict between infection control and having space for medical equipment (p.112)</p> <p>Plwd were still viewed as a person despite admission to acute hospital (p.112)</p> |
| | Barriers of person-centred care | <p>Sitting down with the person was seen as a luxury (p.112)</p> <p>PCC could be overlooked for safety, which may be damaging to dignity (p.112)</p> <p>Routine approaches to chare were not PCC but focussed on physical care (p.112)</p> |
| | Perspective | How the Plwd interacts with the acute setting and what staff do to affect this. |
| | Interactions and the impact on other patients. | <p>The behaviours of the Plwd could impact staff- if they hurt them or shouted at them, as well as impact other patients- if they went into their bedspace (p.112)</p> <p>Sometimes Plwd could not express their needs- impacting their care (p.112)</p> <p>Staff sometimes advocated for Plwd to reduce discrimination, stigmatisation or labelling.</p> |
| | The built environment | The environment was felt to be a hindrance to dementia care due to noise, unfamiliarity- impacting safety, poor layout. (p 113) |
| | Social and psychological | Communication, respect, bonding and family involvement. |
| | “Forming relationships”. | <p>Building relationships was a prerequisite to good care (p.113)</p> <p>Interactions focussed on physical care because staff were uncertain about psychosocial care and communication. (p.113) A lack of time meant opportunities for negotiating care were reduced (p.113)</p> |
| | Family involvement | <p>Family involvement helped individualise care (p113) and helped soothe PLWD</p> <p>Strategies for family involvement were unclear (p113)</p> |

| | | |
|---|---|---|
| | | Family involvement could sometimes cause conflict if they made decisions on behalf of the Plwd (p.113) |
| (Dewing and Dijk, 2016) All view (6) | Consequences of being in hospital | The hospital environment is not dementia friendly and being in hospital can result in negative outcomes- physically (longer stays higher mortality rates, increased falls, functional decline, malnutrition, dehydration, increased reliance on care givers) and emotionally (depression, delirium, pain, fear, thirst, overstimulation). (p.4) Staff may misinterpret behavioural communication of an unmet need as someone being disruptive (p.4) Carers experience a 'cycle of discontent' which could be prevented by better communication (p.4-5) |
| | The care environment | The environment is unsuitable (p.5) Impersonal, busy environment is disorientating (p.5) Adaptions can help such as signage, purposeful activity, headphones, personal objects, minimising clutter (p.5) When staff are not present the anxiety of Plwd raised, when they were present but carrying out tasks it could go positively or negatively (p.5) |
| | Cultures of care | The care needs of Plwd have been underestimated by senior management in the organisation and in national and regional planning (p.5) There is a focus on tasks rather than interaction which means simply increasing staffing may not improve care delivery (p.6) The culture focusses on meeting compliance targets, physical needs and routine resulting in Plwd becoming "objects of care" (p.6) or there is a focus on safety which devalued disorientated people (p.6) PCC is viewed as important but in practice the principles are not applied (p.6) Opportunities to provide PCC are missed (p.6) A therapeutic relationship between the Plwd, their family and the staff can have a positive impact on the Plwd wellbeing (p.7). When staff embrace personhood there are beneficial outcomes (p.7) |
| | Attitudes | The values and beliefs of staff are displayed as action and attitudes (p.7), so addressing staff attitudes can facilitate change. Acute care for co-morbidities may be prioritised rather than dementia care (7) Attitudes to Plwd were variable among staff in the different studies (p.7) |
| | Challenges for people with dementia as an acute 'patient' | Few studies report the views of Plwd. (p8) They have reported the experience as difficult and disturbing (p.8) |

| | | |
|--|--|---|
| | | They felt ignored and found the environment busy and noisy (p.8). Disruption to usual routine could be problematic (p8) Plwd may attempt to exercise some control (p.8) |
| | Challenges for carers | Admission can be physically and emotionally exhausting for carers (p8) Carers attributed functional decline of the Plwd to poor care (p.8)- they did not expect the task-focussed atmosphere (p.8), a “cycle of discontent.” Carers blamed staff for an inflexible system, they were also frustrated by lack of amenities such as chairs or refreshments (p9) Information from carers was felt to be useful but carers could also be viewed as demanding and disruptive (p.9) |
| | Challenges for staff | Non-compliance to care and associated behaviours challenges staff. Staff felt time-pressures and staff shortages impacted their ability to meet this level of care (p.9) When there was poor communication among team’s difficulties were exacerbated (p. 9) Staff did not feel they had the skills or education to meet the needs for Plwd (p9) Staff felt they had to manage disorientated Plwd from interfering with other patients which led to them asking doctors to prescribe sedation (p.10) |
| | Volunteers | When volunteers provide person-centred care staff and volunteers perceive positive outcomes but no differences in length of stay, falls, death rates or use of anti-psychotic drugs were noted. (p.10) |
| | Mental health liaison services/ specialist roles | Specialist mental-health liaison teams may provide in-reach to hospitals for assessments, care plans, education and advice, which can increase detection, diagnosis and staff confidence but there is a lack of evidence. There is a variation in the implementation of these teams, so it is difficult to generalise or evaluate. (p 11) There are also dementia specialist roles which also lack evidence and they may not contribute to upskilling staff (p 11) |
| | Special units/ shared care | These facilities may reduce adverse consequences of stay (reduce falls, improve function) but do not impact on length of stay (p.12) |
| | Education and learning | Dementia care education is felt to impact on the ability for quality care (p.12) Doctors feel more knowledgeable in dementia care than nurses or healthcare assistants (p.12) Not all materials about dementia care education are evaluated (p.12). Some evaluations show improvements in dementia awareness, positive perceptions and attitude, increased confidence, better clinical skills, improved management, better communication between |

| | | |
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| | | <p>staff and relatives, better recognition of pain and a decrease in use of sedatives (p.13)</p> <p>Longer term outcomes are less clear (p.13)</p> <p>Experiential learning or emotional level education has been recommended by some (p13).</p> <p>Implementing changes from training programmes may be stunted by organisational priorities, pressures and targets (p.13)</p> |
| (Brooke and Ojo, 2018) Workforce issues (7) | Understanding the current workforce | <p>Theoretical and practical knowledge of dementia was important for healthcare professionals, people with dementia and their families. (p.e12)</p> <p>Healthcare professionals did not feel their training and prepared them to care for acutely unwell cognitively impaired patients (e12)</p> <p>Plwd and their relatives expected staff to provide tailored, person-centred care (e12)</p> <p>Nurses found it emotionally difficult to implement a PCC approach with increasing workloads, lack of support and this impacted on their wellbeing. They also felt disempowered by their lack of influence on policy, procedure and practice (e.12)</p> <p>Communication was important but difficult, Plwd and their carers felt staff having advanced communication skills was important (e.12), but staff identified difficulties in communicating with Plwd (e12)</p> <p>A well-meaning workforce is not sufficient to provide complex care- Education and training is important for a skilled workforce alongside supportive organisational structures managers and colleagues (e.12- e19)</p> |
| | Implementation and evaluation of training | <p>There were directive and non-directive approaches to training (e-19)</p> <p>There was a brief psychological training intervention to provide staff with practical skills.</p> <p>There was a “Getting to know me” initiative to improve staff knowledge and challenge beliefs about dementia.</p> <p>The non-directive approach was an ethnodrama to emotionally engage staff through a series of films.</p> <p>There were 2 class-room based approaches with adopted module approaches to deliver information.</p> <p>Modules were evaluated using different validated questionnaires or new questionnaires so comparing them was difficult (p.e19)</p> <p>They all reported some positive effects (p.19)</p> <p>Poor attendance was reported at class-room based programmes and poor completion of post-test questionnaires (p.19)- hypothesised as being related to releasing staff from clinical duties.</p> |

| | | |
|--|--|---|
| | | <p>Barbara's story training had support of organisational structures and management up to the Chief nurse and attendance was good (p.e19)</p> <p>A hypothesis has been made that attrition of staff decreases the ability to complete post-test questionnaires to evaluate training (p.e19)</p> |
| | <p>Exploration of new and existing roles</p> | <p>Dementia champions were implemented in Scotland. Healthcare professionals spent half a day in the community with Plwd and their families which challenged their beliefs and views.</p> <p>The professionals reflected that they needed to challenge these views in practice but there were barriers. They implemented changes to the environment, education, identifying Plwd, involving relatives and identifying and managing delirium (p.e.19)</p> <p>Dementia specialist nurse competencies were explored. High levels of knowledge were found within nurses who had a postgraduate degree and were in teams with strong medical model (e.19)</p> <p>They wanted to further understand ethical and legal elements of dementia care and did not feel they had the influence or capacity to develop dementia care as their roles were to support people with dementia to live and cope with diagnosis (e19).</p> |

Appendix 7: Table combining findings into categories and subcategories

| Synthesis | Categories | Category code | Finding | Reference | |
|------------------------|------------------------|--------------------------|---|--|--|
| Organisational aspects | Structural (1) | | Staff were prevented from providing person-centred care | (Gwernan-Jones <i>et al.</i> , 2020) | |
| | | 1a | Performance indicators and ward cultures that prioritised care needs. | (Gwernan-Jones <i>et al.</i> , 2020) | |
| | | 1b | Ward cultures that inhibited the sharing of knowledge across roles and hierarchies, including lack of documentation about personal aspects of PLWD. | (Gwernan-Jones <i>et al.</i> , 2020) | |
| | | 1c | Systems of care | (Reilly and Houghton, 2019) | |
| | | 1d | Organisational Culture and Structure | (Brossard Saxell <i>et al.</i> , 2019) | |
| | | 1e | Adjusting routines and interventions | (Brossard Saxell <i>et al.</i> , 2019) | |
| | | 1f | Pathways of care | (Houghton <i>et al.</i> , 2016) | |
| | | 1g | Culture of care | (Houghton <i>et al.</i> , 2016) | |
| | | 1h | Barriers of person-centred care | (Houghton <i>et al.</i> , 2016) | |
| | | 1i | Consequences of being in hospital | (Dewing and Dijk, 2016) | |
| | | 1j | Cultures of care | (Dewing and Dijk, 2016) | |
| | | Knowledge and skills (2) | 2a | Inadequate levels of training. | (Gwernan-Jones <i>et al.</i> , 2020) |
| | | | 2b | Experiences and Knowledge | (Brossard Saxell <i>et al.</i> , 2019) |
| 2c | Education and learning | | (Dewing and Dijk, 2016) | | |

| | | | | |
|---------------------------|---|----|--|--|
| | | 2d | Implementation and evaluation of training | (Dewing and Dijk, 2016) |
| | | 2e | Understanding the current workforce | (Brooke and Ojo, 2018) |
| | Environment (3) | 3a | Physical environments that prevented familiarisation, social interaction and occupation. | (Gwernan-Jones <i>et al.</i> , 2020) |
| | | 3b | Infrastructures | (Reilly and Houghton, 2019) |
| | | 3c | Physical environment | (Brossard Saxell <i>et al.</i> , 2019) |
| | | 3d | The built environment | (Houghton <i>et al.</i> , 2016) |
| | | 3e | The care environment | (Dewing and Dijk, 2016) |
| | | 3f | Perceived level of independence | (Reilly and Houghton, 2019) |
| | Specialisms (4) | 4a | Volunteers | (Dewing and Dijk, 2016) |
| | | 4b | Mental health liaison services/ specialist roles | (Dewing and Dijk, 2016) |
| | | 4c | Special units/ shared care | (Dewing and Dijk, 2016) |
| | | 4d | Exploration of new and existing roles | (Brooke and Ojo, 2018) |
| Individual aspects | Interpersonal connection (5) | 5a | Not caring for the “person” | (Reilly and Houghton, 2019) |
| | | 5b | Caring for the “person” | (Reilly and Houghton, 2019) |
| | | 5c | Socialising with confidence and autonomy | (Reilly and Houghton, 2019) |
| | | 5d | Establishing Trust | (Brossard Saxell <i>et al.</i> , 2019) |
| | | 5e | “Forming relationships” | (Houghton <i>et al.</i> , 2016) |

| | | | | |
|--|---|-----------|--|--|
| | Getting to know the whole person (6) | 6a | External supports | (Reilly and Houghton, 2019) |
| | | 6b | Forming a Holistic picture | (Brossard Saxell <i>et al.</i> , 2019) |
| | | 6c | “pieces of the puzzle” | (Houghton <i>et al.</i> , 2016) |
| | | 6d | Family involvement | (Houghton <i>et al.</i> , 2016) |
| | Emotions (7) | 7a | The ability of hospital staff to deliver person-centred care was linked to job satisfaction | (Gwernan-Jones <i>et al.</i> , 2020) |
| | | 7b | Conflicts in care. | (Gwernan-Jones <i>et al.</i> , 2020) |
| | | 7c | Coping with emotions. | (Gwernan-Jones <i>et al.</i> , 2020) |
| | | 7d | Job satisfaction. | (Gwernan-Jones <i>et al.</i> , 2020) |
| | | 7e | Disruption and coping | (Reilly and Houghton, 2019) |
| | | 7f | Empathy | (Brossard Saxell <i>et al.</i> , 2019) |
| | | 6h | Interactions and the impact on other patients. | (Houghton <i>et al.</i> , 2016) |
| | | 7i | Challenges for people with dementia as an acute ‘patient’ | Dewing and Dijk, 2016) |
| | | 7j | Challenges for carers | Dewing and Dijk, 2016) |
| | | 7k | Challenges for staff | Dewing and Dijk, 2016) |
| | Values (8) | 8a | Person-centred care aligned with staff perceptions of ‘good care.’ | (Gwernan-Jones <i>et al.</i> , 2020) |
| | | 8b | Values and beliefs | (Brossard Saxell <i>et al.</i> , 2019) |
| | | 8c | Professional identity | (Brossard Saxell <i>et al.</i> , 2019) |
| | | 8d | Attitudes | (Dewing and Dijk, 2016) |

Appendix 8: Letter of ethical approval from NHS Health Research Authority Research Ethics Committee



Health Research Authority

Miss Shanlee Higgins
London South Bank University
School of Health and Social Care
Keyworth Street, London
SE1 6NG

Email: hra.approval@nhs.net

20 November 2017

Dear Miss Higgins

Letter of HRA Approval

| | |
|------------------|---|
| Study title: | A person-centred exploration of oral fluid intake for older people with dementia admitted to acute hospital wards |
| IRAS project ID: | 213936 |
| Protocol number: | NA |
| REC reference: | 17/LO/1335 |
| Sponsor | London South Bank University |

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Page 1 of 8

Appendix 9: Older person living with dementia: participant information leaflet

Oral Fluid Intake for People with Memory Problems in Hospital: Patient Information Sheet

IRAS ID 213936

HSCSEP/17/23

I would like to invite you to take part in a research study. I am a nurse and this research study is part of my post graduate degree course (PhD). Taking part in the study is entirely voluntary and you should only take part if you want to. Before you decide whether to take part, it is important for you to understand why the research is being done and what it would involve for you. Please take your time to read the following information; the researcher can go through this with you and answer any questions you may have.

What is the purpose of the study?

The research aims to explore and describe the care people with memory problems receive in hospital wards. The research will focus on oral fluid intake (drinking) and patient, staff and relative's views on this. The researcher will also look at what the hospital and the hospital staff do to help patients drink, as well as looking at any guidelines the hospital follows promote drinking for older people with memory problems when they are in hospital.

Why me?

You have been invited to take part in this study because you are currently receiving care in an acute hospital ward.

Do I need to take part?

No. Taking part in this study is entirely voluntary and it is up to you to decide whether to take part. Please take your time to think about it and discuss it with your family and friends if you wish.

If you do decide to take part in the research study then you will be asked to sign a consent form. You are free to withdraw from the study at any point and you will not be asked for a reason. Choosing not to take part in the research study, or withdrawing at any time will not affect your clinical treatment within the hospital or impact on your care in any way.

What will happen during the study?

The researcher will observe the care you receive on the ward for 12 hours over two days. You will not be expected to do anything as part of the research while the researcher is observing, just carry on as normal. The researcher will not observe any care that happens behind closed curtains. The researcher will then very briefly interview you to find out about the care you received, particularly about what you have been drinking. This will take approximately 15 minutes. If you feel uncomfortable at any time during the interview, you are free to take a short break or to stop the interview if you wish to.

The researcher will take notes while she is observing your care and after the interview. The results will be anonymous and for use only by the researcher. The researcher will also make notes from your care records about the drinking care you are receiving and talk to staff about how they have been monitoring your drinking.

What are the benefits of taking part?

We do not expect any direct benefit for you from taking part in the study. The information found may help future patients as the results will be shared and could inform future policy, practice and research.

What are the disadvantages of taking part?

We do not expect any disadvantages from taking part in this study. However, some people may find it upsetting to talk about their experiences. The researcher, who is a registered mental health nurse, will support you with any difficult topics. If you feel you would still like to speak to someone once the research has finished you may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

Will my taking part in the study be kept confidential?

All interviews and observations are confidential and you will not be identified in any publication. Individual interviews will not be discussed with the hospital. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the clinical team involved in their medical care. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

What happens to the results of the research study?

The research will be used for a PhD thesis and results may later be presented at conferences and published in journals. Please tell the researcher if you would like a copy of any publications and we would be happy to send them to you when they are published. Your identity will remain confidential and your name will not be identified in any report/publication.

Who is funding and sponsoring the research?

The research is funded by the Mona Grey scholarship and is sponsored by London South Bank University.

Who do I contact for more information?

For more information please contact Shanlee Higgins on:

Phone: 0207 815 8465

Email: higgins4@lsbu.ac.uk

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an NHS Ethics Committee before they can proceed. This proposal was reviewed by [London - Harrow Research Ethics Committee] and has received a Favourable Opinion.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Lesley Baillie [lesley.baillie@open.ac.uk] who is the PhD supervisor.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact Professor Nicola Thomas, who is responsible for the sponsoring of the study.

Her contact details are:

School of Health and Social Care, London South Bank University
103 Borough Road
London
SE1 0AA

T:020 7815 8045 | E: nicola.thomas@lsbu.ac.uk

You can also contact the Patient Advice and Liaison Service on



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 10: Older person living with dementia: Consent form



Oral Fluid Intake for People with Memory Problems in Hospital Patient Consent Form

IRAS ID: 213936

Ethics Committee: HSCSEP/17/23

Researcher: Shanlee Higgins

Supervisors: Dr Lesley Baillie, Associate Professor Calvin Moorley, Professor Fiona Nolan

- | | Please
Initial |
|--|--------------------------|
| 1. I confirm that I have read the information sheet dated 30.09.2017 (Version 2) for the above study. | <input type="checkbox"/> |
| 2. I have had the opportunity to consider the information and ask questions. | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason | <input type="checkbox"/> |
| 4. I give permission for the researcher to audio record the interview. | <input type="checkbox"/> |
| 5. I understand that the data is strictly confidential and anonymous. I also understand that the data will be handled in accordance with the Data Protection Act 1998. | <input type="checkbox"/> |
| 6. I agree to take part in the above study. | <input type="checkbox"/> |

| | | |
|---------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |

When completed: 1 copy for the participant; 1 copy for researcher.

Consent Form: Senior Staff Ward Leadership
Version 1: 5.7.2017

Appendix 11: Consultee information leaflet

Oral Fluid Intake for People with Memory Problems in Hospital

Information for Consultee

IRAS ID: 213936

HSCSEP/17/23

We feel your relative/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should be the priority.

If you decide your relative/friend would have liked to take part in the research or would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should withdraw from the research.

If you decide that your friend/relative would not wish to take part in the research, this will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend.

Oral Fluid Intake for People with Memory Problems in Hospital: Patient Information Sheet

IRAS ID 213936

HSCSEP/17/23

I would like to invite you to take part in a research study. I am a nurse and this research study is part of my post graduate degree course (PhD). Taking part in the study is entirely voluntary and you should only take part if you want to. Before you decide whether to take part, it is important for you to understand why the research is being done and what it would involve for you. Please take your time to read the following information; the researcher can go through this with you and answer any questions you may have.

What is the purpose of the study?

The research aims to explore and describe the care people with memory problems receive in hospital wards. The research will focus on oral fluid intake (drinking) and patient, staff and relative's views on this. The researcher will also look at what the hospital and the hospital staff do to help patients drink, as well as looking at any guidelines the hospital follows promote drinking for older people with memory problems when they are in hospital.

Why me?

You have been invited to take part in this study because you are currently receiving care in an acute hospital ward.

Do I need to take part?

No. Taking part in this study is entirely voluntary and it is up to you to decide whether to take part. Please take your time to think about it and discuss it with your family and friends if you wish. If you do decide to take part in the research study then you will be asked to sign a consent form. You are free to withdraw from

the study at any point and you will not be asked for a reason. Choosing not to take part in the research study, or withdrawing at any time will not affect your clinical treatment within the hospital or impact on your care in any way.

What will happen during the study?

The researcher will observe the care you receive on the ward for 12 hours over two days. You will not be expected to do anything as part of the research while the researcher is observing, just carry on as normal. The researcher will not observe any care that happens behind closed curtains. The researcher will then very briefly interview you to find out about the care you received, particularly about what you have been drinking. This will take approximately 15 minutes. If you feel uncomfortable at any time during the interview, you are free to take a short break or to stop the interview if you wish to.

The researcher will take notes while she is observing your care and after the interview. The results will be anonymous and for use only by the researcher. The researcher will also make notes from your care records about the drinking care you are receiving and talk to staff about how they have been monitoring your drinking.

What are the benefits of taking part?

We do not expect any direct benefit for you from taking part in the study. The information found may help future patients as the results will be shared and could inform future policy, practice and research.

What are the disadvantages of taking part?

We do not expect any disadvantages from taking part in this study. However, some people may find it upsetting to talk about their experiences. The researcher, who is a registered mental health nurse, will support you with any difficult topics. If you feel you would still like to speak to someone once the research has finished you

may also find it helpful to ring the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9am to 5pm Monday to Friday and Saturday and Sunday 10am - 4pm.

Will my taking part in the study be kept confidential?

All interviews and observations are confidential and you will not be identified in any publication. Individual interviews will not be discussed with the hospital. If any person in the study tells us that they or someone else is being harmed we will ask their permission to disclose the information to the clinical team involved in their medical care. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

What happens to the results of the research study?

The research will be used for a PhD thesis and results may later be presented at conferences and published in journals Please tell the researcher if you would like a copy of any publications and we would be happy to send them to you when they are published. Your identity will remain confidential and your name will not be identified in any report/publication.

Who is funding and sponsoring the research?

The research is funded by the Mona Grey scholarship and is sponsored by London South Bank University.

Who do I contact for more information?

For more information please contact Shanlee Higgins on:

Phone: 0207 815 8465

Email: higgins4@lsbu.ac.uk

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an NHS Ethics Committee before they can proceed. This proposal was reviewed by [London - Harrow Research Ethics Committee] and has received a Favourable Opinion.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Lesley Baillie [lesley.baillie@open.ac.uk] who is the PhD supervisor.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact Professor Nicola Thomas, who is responsible for the sponsoring of the study.

Her contact details are:

School of Health and Social Care, London South Bank University

103 Borough Road

London

SE1 0AA

T:020 7815 8045 | E: nicola.thomas@lsbu.ac.uk

You can also contact the Patient Advice and Liaison Service on [REDACTED]

[REDACTED]

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 12: Consultee declaration form



Oral Fluid Intake for People with Memory Problems in Hospital

Consultee Declaration Form

IRAS Project ID: 213936

HSCSEP/17/23

Researcher: Shanlee Higgins

Supervisors: Dr Lesley Baillie, Dr Calvin Moorley, Professor Fiona Nolan

Please initial box

I _____ [please enter name of consultee] have been consulted about _____ [please enter name of patient] participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.

In my opinion he/she would have no objection to taking part in the above study.

I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.

I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from London South Bank University or University College Hospital or from regulatory authorities, where it is relevant to their taking part in this research.

Name of Consultee

Date

Signature

Relationship to participant:

Person undertaking consultation (if different from researcher):

Name

Date

Signature

Researcher

Date

Signature

When completed: 1 (original) to be kept in care record, 1 for consultee; 1 for researcher site file

Consultee declaration 5.7.2017

Appendix 13: Relatives participant information leaflet

Oral Fluid Intake for People with Memory Problems in Hospital: Relative Information Sheet

IRAS ID: 213936

HSCSEP/17/23

I would like to invite you to take part in a research study. I am a nurse and this research study is part of my post graduate degree course (PhD). Taking part in the study is entirely voluntary, and you should only take part if you want to. Before you decide whether to take part, it is important for you to understand why the research is being done and what it would involve for you. Please take your time to read the following information; the researcher can go through this with you and answer any questions you may have.

What is the purpose of the study?

The research aims to explore and describe the care people with memory problems receive in hospital wards. The research will focus on oral fluid intake (drinking) and patient, staff and relative views on this. The researcher will also look at what the hospital and the hospital staff do to help patients drink, as well as looking at any guidelines the hospital follows to promote drinking for older people with memory problems when they are in hospital.

Why me?

You have been invited to take part in this study because a relative of yours is currently receiving care on this ward and they are part of the research study.

Do I need to take part?

No. Taking part in this study is entirely voluntary, and it is up to you to decide whether or not to take part. Please take your time to think about it and discuss it with your family and friends if you wish.

If you do decide to take part in the research study, then you will be asked to sign a consent form. You are free to withdraw from the study at any point, and you will not be asked for a reason. Choosing not to take part in the research study, or

withdrawing at any point will not affect your relative's treatment within the hospital or impact on their care in any way.

What will happen during the study?

The researcher will interview you to find out about the care your relative is receiving, particularly about what they have been drinking. If you feel uncomfortable at any time during the interview, you are free to take a short break or to stop the interview if you wish to.

The interview will be audio recorded and then typed up by the researcher any identifiable information will be edited. All audio recordings will then be destroyed. The results will be anonymous and for use only by the researcher

What are the benefits of taking part?

We do not anticipate any direct benefit for you taking part in the study. The information found may help future patients as the results will be shared and could inform future policy, practice and research.

What are the disadvantages of taking part?

We do not anticipate any disadvantages from taking part in this study. However, some people may find it upsetting to talk about their experiences. The researcher, who is a registered mental health nurse, will support you with any difficult topics. If you feel you would still like to speak to someone once the research has finished, you may also find it helpful to speak to the the Alzheimer's Society National Dementia Helpline on 0300 222 1122. The Helpline is usually open from 9 am to 5 pm Monday to Friday and Saturday, and Sunday 10 am - 4 pm.

Will my taking part in the study be kept confidential?

All interviews and observations are confidential, and you will not be identified in any publication. Individual interviews will not be discussed with the hospital. If any person in the study tells us that they or someone else is being harmed, we will ask their permission to disclose the information to the clinical team involved in their medical care. We respect confidentiality but cannot keep it a secret if anyone is being harmed.

What happens to the results of the research study?

The research will be used for a PhD thesis and results may subsequently be published in conference proceedings and publications. Please tell the researcher if you would like a copy of any publications and we would be happy to send them to you when they are published. Your identity will remain confidential, and your name will not be identified in any report/publication.

Who is funding and sponsoring the research?

The research is funded by the Mona Grey scholarship and is sponsored by London South Bank University.

Who do I contact for more information?

For more information, please contact Shanlee Higgins on:

Phone: 0207 815 8465

Email: higgins4@lsbu.ac.uk

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an NHS Ethics Committee before they can proceed. This proposal was reviewed by [London - Harrow Research Ethics Committee] and has received a Favourable Opinion.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Lesley Baillie [lesley.baillie@open.ac.uk] who is the PhD supervisor.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during this study, you may contact Professor Nicola Thomas, who is responsible for the sponsoring of the study.

Her contact details are:

School of Health and Social Care, London South Bank University

103 Borough Road

London

SE1 0AA

T:020 7815 8045 | E: nicola.thomas@lsbu.ac.uk

You can also contact the Patient Advice and Liaison Service on



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 14: Relatives consent form



Oral Fluid Intake for People with Memory Problems in Hospital Relative Participant Consent Form

IRAS Project ID: 213936

HSCSEP/17/23

Researchers: Shanlee Higgins (Researcher)

Dr Lesley Baillie, Dr Calvin Moorley, Professor Fiona Nolan (Supervisors)

- | | Please
Initial |
|---|--------------------------|
| 1. I confirm that I have read the information sheet dated 30.8.2017 (Version 2) for the above study. | <input type="checkbox"/> |
| 2. I have had the opportunity to consider the information and ask questions. | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without this affecting my relative's care. | <input type="checkbox"/> |
| 4. I give permission for the researcher to audio record the interview on the condition that all identifying information will be anonymised. | <input type="checkbox"/> |
| 5. I understand that the data is strictly confidential and anonymous. I also understand that the data will be handled in accordance with the Data Protection Act 1998. | <input type="checkbox"/> |
| 6. I agree to take part in the above study. | <input type="checkbox"/> |

| | | |
|---------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |

When completed: 1 copy for the participant; 1 copy for researcher; 1 (original copy)

Consent Form: Relative consent
Version 1: 5/7/2017

Appendix 15: Ward information for ward sisters and matrons

Information for Ward Sisters and Matrons for the Research Study: Person-centred Fundamental Hydration care for People with Dementia in Acute Hospitals

Background

There are high numbers of people with dementia in NHS hospitals. Approximately 43 percent of people admitted to UK hospitals non-electively are over-65s (Oliver, Foot and Humphries, 2014) and a quarter of those are living with dementia (Care Quality Commission [CQC], 2014) (Care Quality Commission, 2014). Policy suggests care for people with dementia should be person-centred. However, studies have highlighted that person-centred care is challenging to implement in acute hospitals. To implement person-centred care, fundamental care needs must be addressed. People with dementia are more likely to require support with fundamental care, such as help with eating and drinking. There is limited research conducted in acute hospitals about the fundamental care of people with dementia when admitted to acute wards. Most research about fundamental care has focused on nursing care only, despite hospitals being multi-disciplinary environments. In acute hospitals care needs are met by a multi-disciplinary team of health-care professionals and support staff. This study aims to address the gap in knowledge relating to how oral fluid intake is managed for people with dementia when they are admitted to hospital.

Aim

To explore and describe the factors influencing oral fluid intake and associated experience for people with dementia in acute hospital wards.

Methods

This qualitative study will use a range of methods to collect data. There are two parts to the study.

- 1) The first part is to understand the hospital context. To do this I will:
 - Conduct an interview with senior staff who have a leadership role for the whole hospital about how person-centred care is facilitated in the hospital.
- 2) The second part will take place within three wards in the hospital and will consist of:
 - An interview with a member of staff who has a leadership role on the ward; this will be about person-centred care and oral fluid intake. The researcher will ask about any policies or procedures that guide practice.
 - Observation of the care a person with dementia receives over two days, this will be four observation periods of four hours each (7am-11am, 11am-3pm, 3pm-7pm, 7pm-11pm).
 - Analysis of patient documentation (multi-disciplinary and nursing records).
 - An interview about fluid intake with the person with dementia.
 - An interview about fluid intake with relative of the person with dementia.
 - Brief interviews (approx. 5 minutes) with staff who have interacted with the person with dementia who is being observed regarding fluid intake and their role.

Shanlee Higgins, PhD Research Information

e: higgins4@lsbu.ac.uk

Sample

| | |
|--|-------------------------|
| Part one | |
| Senior staff (Trust-wide leadership role) | Minimum= 3 Maximum = 5 |
| Part two (number per ward) | |
| Senior healthcare staff (Ward leadership role) | 1 |
| People with dementia | Minimum = 3 Maximum = 5 |
| Staff working with the person with dementia | Minimum = 3 Maximum = 5 |
| Relatives | Minimum = 3 Maximum = 5 |

Exclusion

A patient that fits either of the following criteria will be excluded:
 Has dysphagia and is receiving thickened drinks.
 Is receiving IV fluids **only** and not receiving any oral fluid.

What I will require from the wards

1. Ward manager to give their consent for the ward to take part in the study.
2. An email to be sent to all staff working on the ward, including an invitation letter, information about the study and information about how to opt out of the research. This will be a standard letter template I will give to the ward manager.
3. Support to identify people with dementia on the ward who may consent to the research.
4. A member of the ward staff (usually the staff nurse) to approach the person with dementia or their family member- if they do not have capacity to consent- to ask if they will speak to a researcher.
5. Ward manager to communicate to staff that they are permitted to take five minutes to complete a brief interview about the person with dementia's care- if the staff member consents to do so.
6. A place to put up a research poster for staff and patients to see
7. It may be useful for me to attend team meetings or handovers to explain the study – and my presence on the ward.
8. An agreement about who to inform should any unsafe practice be highlighted, usually this would be the ward sister.

Shanlee Higgins, PhD Research Information

e: higgins4@lsbu.ac.uk m: [REDACTED]

Appendix 16: Ward leader information sheet

Oral Fluid Intake for People with Dementia in Hospital: Senior Staff Ward Leadership information sheet

IRAS ID: 213936

I would like to invite you to take part in a research study. Taking part in the study is entirely voluntary, and you should only participate if you want to. Before you decide whether to take part, it is important for you to understand why the research is being done and what it would involve for you. Please take your time to read the following information; the researcher can go through this with you and answer any questions you may have.

What is the purpose of the study?

The research aims to explore and describe the care people with memory problems receive in hospital wards. The research will focus on oral fluid intake and patient, staff and relative views on this. The researcher will also look at what members of staff do to help patients drink and any hospital procedures that promote oral fluid intake for older people with memory problems when they are in the hospital.

Why me?

You have been invited to take part in this study because you are a senior member of staff with a leadership role on one of the wards that will be studied.

Do I have to take part?

No. Taking part in this study is entirely voluntary, and it is up to you to decide whether or not to take part. Please take your time to think about it and ask the researcher any questions you have.

If you do decide to take part in the research study, then you will be asked to sign a consent form. You are free to withdraw from the study at any point, and you will not be asked for a reason.

What will happen during the study?

The researcher will ask you questions on a series of topics related to dementia and oral fluid intake care in the hospital. The interview will be audio recorded and then transcribed by the researcher. All responses will be confidential. The researcher will also ask you if there are any policies, strategies or initiatives that demonstrate how the ward promotes quality dementia care or oral fluid intake and where these documents can be accessed.

What are the benefits of taking part?

We do not anticipate any direct benefit for you taking part in the study. The information found will be used to inform policy, practice and future research.

What are the disadvantages of taking part?

We do not anticipate any disadvantages from taking part in this study.

Will my taking part in the study be kept confidential?

All interviews are confidential, and you will not be identified in any publication. Individual interviews will not be discussed with the hospital.

What happens to the results of the research study?

The research will be used for a PhD thesis and results may be presented at conferences and published in journals. Please tell the researcher if you would like a copy of any publications and we would be happy to send them to you when they are published. Your identity will remain confidential, and your name will not be identified in any report/publication.

Who is funding and sponsoring the research?

The research is funded by the Mona Grey Scholarship and is sponsored by London South Bank University.

Who do I contact for more information?

For more information, please contact Shanlee Higgins on:

Phone: 0207 815 8465

Email: higgins4@lsbu.ac.uk

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an NHS Ethics Committee before they can proceed. This proposal was reviewed by [INSERT NAME OF REC] and has received a Favourable Opinion.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Lesley Baillie who is the PhD supervisor.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during this study, you may contact Professor Nicola Thomas, who is responsible for the sponsoring of the study.

Her contact details are:

School of Health and Social Care, London South Bank University

103 Borough Road

London

SE1 0AA

T:020 7815 8045 | E: nicola.thomas@lsbu.ac.uk

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 the time to read this sheet.

Appendix 17: Ward environment consent form



Oral Fluid Intake for People with Memory Problems in Hospital Ward Environment Consent Form

IRAS ID: 213936

HSCSEP/17/23

Researchers: Shanlee Higgins (Researcher)

Supervisors: Dr Lesley Baillie, Associate Professor Calvin Moorley, Professor Fiona Nolan

- | | Please
Initial |
|---|--------------------------|
| 1. I confirm that I have read the information sheet dated 12.09.2017 (Version 1) for the above study. | <input type="checkbox"/> |
| 2. I have had the opportunity to consider the information and ask questions. | <input type="checkbox"/> |
| 3. I understand that the ward participation is voluntary | <input type="checkbox"/> |
| 4. I give permission for the researcher to talk to staff on the ward and for staff to contact relatives to gain permission for the researcher to contact them with the study details. | <input type="checkbox"/> |
| 5. I understand that the data is strictly confidential and anonymous. I also understand that the data will be handled in accordance with the Data Protection Act 1998. | <input type="checkbox"/> |
| 6. I agree for the ward to be part of the above study. | <input type="checkbox"/> |

| | | |
|---------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |

When completed: 1 copy for the participant; 1 copy for researcher.

Consent Form: Ward environment
Version 2 : 25.01.2018

Appendix 18: Email sent to all staff on the ward

Shanlee Higgins

London South Bank University
School of Health and Social Care
K2 Building
Keyworth Street
SE1 6NG

T: 0207 8158465

E: [REDACTED]

[Insert date]

[Insert ward name] – All Staff

Address removed

for confidentiality

Dear All staff on [ward name]

I am a PhD student and Mental Health Liaison Nurse. I am writing to you as I am conducting my PhD research on this ward. Please read the information sheet included for more information about the research.

The ward sister [insert name] and matron [insert name] have agreed for the research to take place on the ward. This study involves observation of care being given to patients who have consented to being observed. If you would prefer not to be observed or would like to discuss any details further, please contact me by email or phone (my contact details are below) or speak to me when I am on the ward.

[REDACTED]

[You can also let me know about your decision to opt out when I am on the ward.](#)

I look forward to collecting data here in the following months.

Yours Sincerely,

Shanlee Higgins

Appendix 19: Research Poster



Recruiting for Research



This ward is part of a research study taking place right now!

The research will explore the experience of people with dementia when they are admitted to hospital, especially the drinks they receive.

If you are a patient, relative or staff member and would like more information about the research please speak to the researcher Shanlee Higgins or talk to the ward sister.



Shanlee Higgins
Researcher

higgins4@lsbu.ac.uk

Work telephone:
020 7815 8465



Appendix 20: Ward leader consent form

Oral Fluid Intake for People with Dementia in Hospital Senior Staff Ward Leadership Consent Form

Researcher: Shanlee Higgins

Supervisors: Dr Lesley Baillie, Associate Professor Calvin Moorley, Professor Fiona Nolan

IRAS ID: 213936

- | | Please
Initial |
|--|--------------------------|
| 1. I confirm that I have read the information sheet dated 5/7/2017 (Version 1) for the above study. | <input type="checkbox"/> |
| 2. I have had the opportunity to consider the information and ask questions. | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason | <input type="checkbox"/> |
| 4. I give permission for the researcher to audio record the interview. | <input type="checkbox"/> |
| 5. I understand that the data is strictly confidential and anonymous. I also understand that the data will be handled in accordance with the Data Protection Act 1998. | <input type="checkbox"/> |
| 6. I agree to take part in the above study. | <input type="checkbox"/> |

| | | |
|---------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |

| | | |
|--------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |

When completed: 1 copy for the participant; 1 copy for researcher.

Consent Form: Senior Staff Ward Leadership
Version 1, Date : 5.7.2017

Appendix 21: Ward staff information sheet

Oral Fluid Intake for People with Dementia in Hospital: Ward Staff information sheet

**A study into experiences of older people with dementia in acute
hospital wards related to fluid intake**

IRAS ID: 213936

HSCSEP/17/23

I would like to inform you about a research study that is going to take place on this ward. I am a nurse and this research is part of my post-graduate degree course (PhD). If you do not want to participate in this study, in the way described below, please let me know, using the email address or phone number below. Before you decide whether to take part, it is important for you to understand why the research is being done and what it would involve for you.

What is the purpose of the study?

The research aims to explore and describe the care people with memory problems receive in hospital wards. The research topic is oral fluid intake (drinking) and patient, staff and relative's views on this. I will also look at what members of staff do to help patients drink and any hospital procedures that promote oral fluid intake for older people with memory problems when they are in the hospital.

Why me?

You are receiving this information because you are a member of staff on a ward that is taking part in the research and it is possible that you will be working with a patient that has consented to take part in this research study.

Do I need to take part?

No. Taking part in this study is entirely voluntary, and it is up to you to decide whether or not to take part, choosing not to take part in the research or withdrawing at any point will not affect your job. If you do decide you would not like to be part of the research study, then you will need to respond to me by email, by phone or tell me verbally when I am on the ward that you wish to opt out. You are free to withdraw from the study at any point, and you will not be asked for a reason.

What will happen during the study?

I will be present on the ward. If a patient consent into the study, I will observe the care they receive. I will make notes about the interactions staff have with the patient and the patient documentation. You will not need to do anything, just carry on as you normally would. I may ask you to take part in an interview following the observation, but this will be discussed on the day and you can choose not to take part in an interview.

What are the benefits of taking part?

I do not anticipate any direct benefit for you taking part in the study. The information found will be used to inform policy, practice and future research.

What are the disadvantages of taking part?

There are no disadvantages anticipated for those that participant in this study. I do not anticipate any disadvantages from taking part in this study.

Will my taking part in the study be kept confidential?

All observations and notes made are confidential, and you will not be identified in any publication or report. The data will not be discussed with your peers, managers or others within your employing organisation. However, if there are any incidents of concern about potential harm to patients or others, I have a duty to report this, with or without your permission. You will be informed if this happens.

What happens to the results of the research study?

The research will be used for my PhD thesis and results may subsequently be presented at conferences and published in journals. Please tell me if you would like a copy of any reports or publications and I would be happy to send them to you Your identity will remain confidential at all times.

Who is funding and sponsoring the research?

The research is funded through a bequest known as the Mona Grey Scholarship and is sponsored by London South Bank University.

Who do I contact for more information?

For more information, or to opt out please contact me (Shanlee Higgins) on the ward or by phone or email, details below:

Phone: 0207 815 8465

Email: higgins4@lsbu.ac.uk

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an NHS Ethics Committee before they can proceed. This proposal was reviewed by London - Harrow Research Ethics Committee and has received a favourable opinion.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Lesley Baillie [lesley.baillie@open.ac.uk] who is the principal PhD supervisor.

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during this study, you may contact Professor Nicola Thomas, who is responsible for the sponsoring of the study. Her contact details are:

School of Health and Social Care, London South Bank University
103 Borough Road
London
SE1 0AA
T:020 7815 8045 | E: nicola.thomas@lsbu.ac.uk

You will be given a copy of this information sheet and a signed consent form to keep.

Thank you for considering participating in the study and taking the time to read this information.

Appendix 22: Ward staff consent form



Oral Fluid Intake for People with Dementia in Hospital Ward Staff Consent Form

IRAS ID: 213936

HSCSEP/17/23

Researcher: Shanlee Higgins

Supervisors: Dr Lesley Baillie, Associate Professor Calvin Moorley, Professor Fiona Nolan

- | | Please
Initial |
|--|--------------------------|
| 1. I confirm that I have read the information sheet dated 30.8.2017 (Version 2) for the above study. | <input type="checkbox"/> |
| 2. I have had the opportunity to consider the information and ask questions. | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason | <input type="checkbox"/> |
| 4. I give permission for the researcher to audio record the interview. | <input type="checkbox"/> |
| 5. I understand that the data is strictly confidential and anonymous. I also understand that the data will be handled in accordance with the Data Protection Act 1998. | <input type="checkbox"/> |
| 6. I agree to take part in the above study. | <input type="checkbox"/> |

| | | |
|---------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |

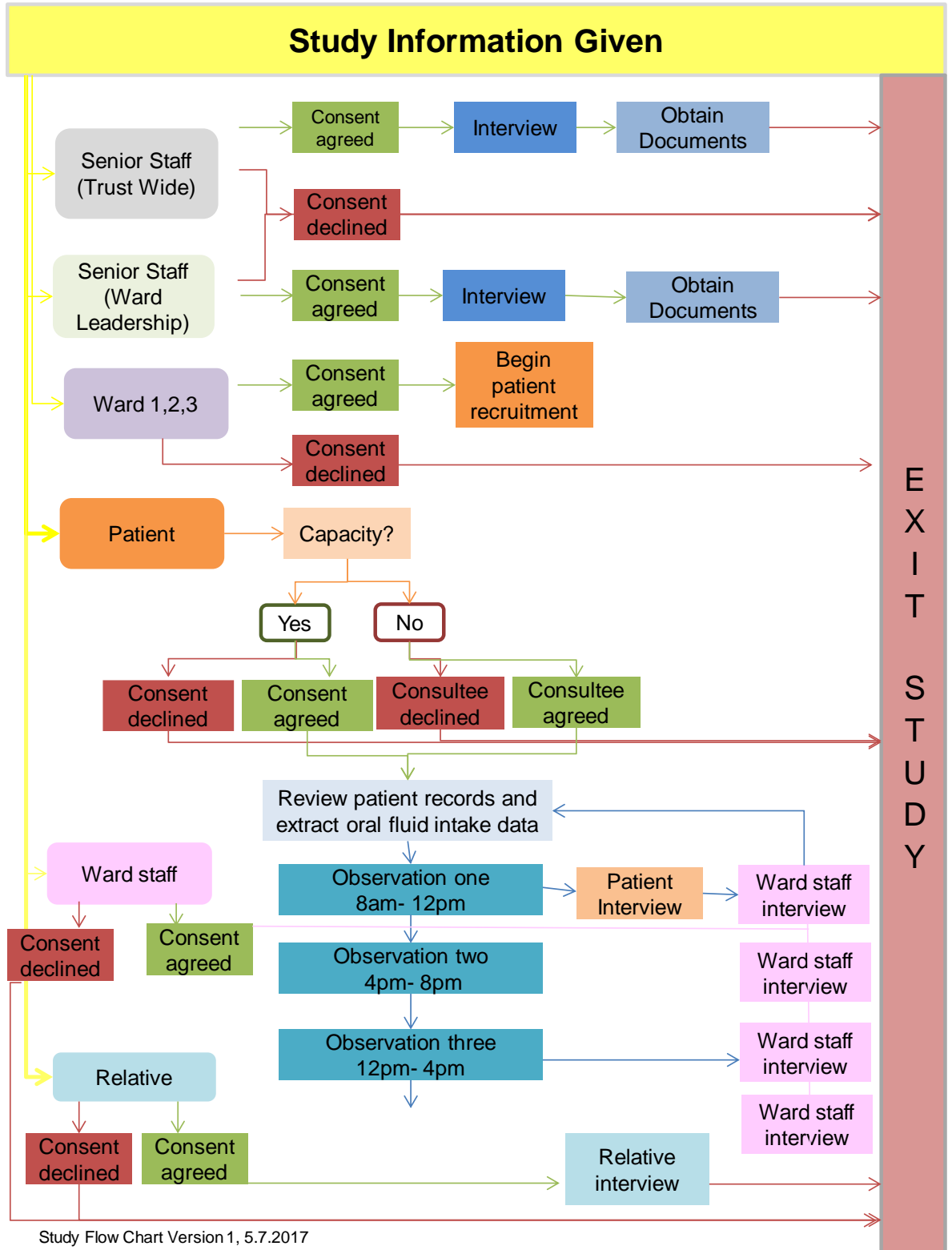
| | | |
|--------------------|-------|-----------|
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |

When completed: 1 copy for the participant; 1 copy for researcher.

Consent Form: Ward staff

Version 1: 5.7.2017

Appendix 23: A flowchart of the study entry and exit points, with consent and data collection



Appendix 24: Interview topic guide: Senior staff Trust-wide

Interview topic guide: Senior Staff Trust-wide

The questions are a guide – follow-up probes will be asked to explore responses related to the topics further.

Introduction:

My name is [researcher name] I am researching person-centred dementia care in acute hospitals; especially the fundamental care need of oral fluid intake. The definition of person-centred care I am using is from the “VIPS framework” (Brooker and Latham, 2016).

They define person centred care as:

V: A value base that asserts the absolute value of all human lives regardless of age or cognitive ability

I: An individualised approach, recognising uniqueness.

P: Understanding the world from the perspective of the person identified as needing support

S: Providing a social environment that supports psychological needs.

The questions I will be asking are developed from the topics within this framework.

Management:

- How do nursing leaders in this organisation support staff in working with people with dementia?
Prompt: are there specific posts that exist with particular reference to helping staff build confidence and skills in this area?

Vision:

- Is person-centred care for people with dementia facilitated within the trust? If yes, how?
- Can you describe how person-centred care is included in any vision statements or policy documents for this organisation?
- Are there strategies to support fundamental care needs, including oral fluid intake, for people with dementia?

Prompt: Please expand on these, or if none exist, potential reasons for their absence

Training and staff development:

- Does dementia awareness feature in the Trust induction?

Prompt: if so- What does it include and for which staff?

- What other dementia training do staff receive?
 - *Prompt- is it different for different professions? What does it consist of...person-centred care, fundamental care needs?*

Service environments:

- How are inpatient ward environments adapted to care for people in a person-centred way?
- Are there any specific strategies to improve/ monitor fundamental care?
 - *Prompt: If so- Does this include oral fluid intake?*
 - *Which staff are involved in facilitating oral fluid intake?*

Quality assurances:

- How is the quality of dementia care measured in this organisation?
- Are there processes in this organisation to gain feedback from people with dementia and their carers on the care they have received?
 - *Prompt: if they give feedback are there processes to act on their suggestions?*

Are there any other comments you would like to add about person-centred and fundamental care or oral fluid intake for people with dementia in the Trust?

Appendix 25: Interview topic guide: Staff with ward leadership role

Interview topic guide: Staff with ward leadership role

The questions are a guide – follow-up probes will be asked to explore responses related to the topics further.

Introduction:

My name is Shanlee Higgins I am researching person-centred dementia care in acute hospitals; especially the fundamental care need of oral fluid intake.

The definition of Fundamentals of care I am using is Feo and Kitson's (2016) working definition of the fundamentals of care which is:

“Essential elements of care, encompassing physical, psychosocial and relational aspects, that are required by every patient regardless of their clinical condition or the setting in which they are receiving care”

The definition of person-centred care I am using is from the “VIPS framework” (Brooker and Latham, 2016).

They define person centred care as:

V: A value base that asserts the absolute value of all human lives regardless of age or cognitive ability

I: An individualised approach, recognising uniqueness.

P: Understanding the world from the perspective of the person identified as needing support

S: Providing a social environment that supports psychological needs.

The questions I will be asking are developed from the topics within this framework. They will cover areas including policies, care, organization and quality. I hope the responses will provide me with an understanding of the context and environment that care takes place in. If any policies are discussed, I would be grateful for a copy of them following the interview.

Could you tell me a bit about hydration / oral fluid intake for people with dementia on this ward?

Policies:

- Are there policies or guidelines about dementia care, fundamental care needs or oral fluid intake on the ward, this could be local ward level policies and guidelines or Trust wide?

Prompt: If yes, ask for further information about these documents

Care:

- Are there any organisational guidelines available to support fundamental care for people with dementia on the ward?

Prompt: What are they? Who is responsible for delivering them?

Prompt: how about strategies to support people with dementia with oral fluid intake?

Prompt: How about in patient records or care plans?

Feedback/ quality:

- Are there ways for patients with dementia or their relatives to feedback their opinion of ward care?

If yes: can you describe them?

- *Prompt: Are patients and relatives informed of these? How?*
- *Prompt: Is there a system/ procedure to discuss these suggestions with ward staff? Explore response.*
- *Prompt: Is there a system to make improvements based on the feedback? Explore response.*
- *Prompt: Is oral fluid intake a topic that family or older people with dementia make comments about? Explore response.*

If no: can you say a little about what you think should be in place?

- Is there a way for staff to suggest improvements about the care of people with dementia and their fundamental care needs?
 - *Prompt: Is there a system to discuss these suggestions with ward staff? Explore response.*
 - *Prompt: Is there a system to make improvements based on the feedback? Explore response.*
 - *Prompt: Is oral fluid intake a topic that staff make comments about? Explore response.*

Organisation:

- Does the ward environment influence person-centred care?

Prompt: In what ways?

Prompt: How do senior staff, i.e., band 7 or above facilitate a person-centred culture?

- Do senior trust staff promote person-centred care among staff?

Prompt: In what ways?

Other:

- Is there anything else you would like to say about person-centred care for people with dementia on the ward and oral fluid intake particularly?

Appendix 26: Interview topic guide: Staff caring for older people living with dementia interview

Topic Guide: Ward Staff

Interviews with ward staff will be conducted following an observation period and will be with staff members who have interacted with the patient in the observation period and been involved with providing oral fluids and/or helping the patient to drink. Questions will be tailored to the observation.

Introduction: I'm carrying out research on the ward about the experience of people with dementia in hospital, it's especially about person-centred care and oral fluid intake (drinking).

I'd like to ask you some questions about your interactions with [patient's name].

- What do you see as your role within the care and management of oral fluid intake?
- What do you feel helps to support [patient's name] with their oral fluid intake?
 - *Prompt: Are there any other ways that oral fluid intake could be improved for [patient's name]?*
- Did you know what type of oral fluid they prefer?
Prompt: Explore response
- Can you see any barriers to supporting [patient's name] with oral fluid intake?
Prompt: Explore response
- What was your goal when interacting with [patient's name]?
- Is there anything else you would like to add about oral fluid intake for [patient's name] or for other patients with dementia?

Appendix 27: Interview topic guide: Older person living with dementia participant interview

Patient Interview Topic Guide: Part One (Fluid intake in Hospital)

I am carrying out research about the care on this ward.

I would like to ask you some questions about your experience.

I am especially interested in the care you are receiving and the drinks you have been given.

Is it ok for me to ask you some questions now?

The researcher will ask the following questions with follow up prompts to find out more information

1) Have you been asked which drinks you like?

Yes



No



Prompts: by whom?

2) What do you think about the choice of drinks on offer?



Very good

Adequate

Not very good

Prompts: Did you get a choice? Were they the drinks you like? Did you need help?

Did you have enough?

3) Can you get a drink when you want one?

Prompt- how do you feel about that?

4) Are the drinks served in the type of cup that you like?

Yes



No



5) Do you have any other comments about the drinks on this ward?

Patient Interview Topic Guide: Part Two (Fluid intake at Home)

I am carrying out research about the care on this ward. We talked about the drinks you have in hospital.

I am also interested in what you drink at home.

Is it ok for me to ask you some questions now?

The researcher will ask the following questions with follow up prompts to find out more information

1) What do you drink when you are at home?



Prompts: Hot drinks? Cold drinks?

2) When do you drink at home?

Prompts: With your meal? In between meals?



3) What times of day do you drink?



4) Do you have any help making drinks at home?

Prompts: What do you do? Who helps?

5) Do you think that the drinks in the hospital could be improved?

Prompts: In what way?

Appendix 28: Topic Guide: Relative Interview

Relative Interview Topic Guide

The researcher will begin by explaining what the interview is about and check the relative is happy to be asked some questions.

I am carrying out research about care on this ward. I would like to ask some questions about your relative's experience and your opinion. I am especially interested in what people drink in hospital and what they drink at home.

Is it ok for me to ask some questions?

The researcher will facilitate a discussion around the following topics.

Drinking in hospital

- What has your relative been drinking in hospital?
- Can your relative express their wishes around drinks?
- Have they been asked their preferences for drinks?
 - *Prompt: have you been asked what your relative's preferences are?*
- Does your relative need any help with drinking?
 - *Prompt: have they been offered help to your knowledge?*

Drinking at home

- What does your relative drink at home?
- Are there any differences in what your relative drinks at home and what they drink in hospital? If yes, can you describe.
- Does your relative need help with drinking at home?
 - *If yes, what sort of help*
- Has the amount of help they need in hospital changed compared to the help they usually have with drinks at home?
 - *If yes, how?*

Other

- What do you think about the drinks offered in hospital?
 - *Explore responses.*
- Have you got any other comments about the drinks in hospital, i.e., any suggestions for improvement? Or anything you think works well?

Appendix 29: Nursing clinical records data extraction document

Data extraction: Patient records– nursing specific records

| Date: | Time: | Patient Identifier: |
|---|---|-----------------------------------|
| <div style="border: 2px solid green; padding: 5px; display: inline-block;"> Patient Profile I.e. "This is Me" or equivalent </div> | Is there a this is me document? | Yes/No |
| | Is it filled in? | Yes/No |
| | By who? | _____ |
| | Is there any information about fluid Intake? If yes, what is written? | Yes/No _____ _____ _____ |
| <div style="border: 2px solid blue; padding: 5px; display: inline-block;"> Fluid charts </div> | Is there a fluid input or output chart in place? | What is the plan? _____ |
| | Is it being used? | Yes/ No |
| | Are the types of drinks offered and consumed recorded? | Yes/ No |
| | How often are people having drinks? | _____ |
| | Has a care plan been created regarding oral fluid intake? | Yes/No _____ |
| <div style="border: 2px solid red; padding: 5px; display: inline-block;"> Malnutrition Universal Screening Tool </div> | What is the MUST score? | _____ |
| | Has a care plan been created? | _____ |
| | If yes, what is included? | _____ _____ _____ _____ |
| <div style="border: 2px solid purple; padding: 5px; display: inline-block;"> Daily activity record sheet </div> | Is there a daily activity record? | Yes/No |
| | Is there anything recorded about fluid intake? (Describe) | _____ _____ _____ _____ |
| <div style="border: 2px solid black; padding: 5px; display: inline-block;"> Any other documents or care plans? </div> | Any other care plans or assessments that are about the patient's fluid intake or person-centred care? | _____ |
| | If yes record details | _____ _____ _____ _____ |

Data extraction: Nursing V1 13.7.2017

Appendix 30: Multi-disciplinary clinical records data extraction document

Data Extraction: Multi-disciplinary patient records

Read the patient multi-disciplinary records to find any records that discuss oral fluid intake, hydration or dehydration and extract information to answer the following questions. Record the full sentence, word for word if oral fluid intake is included in the notes.

Date:

Time:

Patient Identifier:

| | |
|---|--|
| <p>Medical (ward round) What has been written?</p> <p>What date?</p> <p>Which professional and their grade recorded it?</p> <p>Any care plans created?</p> <p>Any referrals?</p> | |
| <p>Medical (other)</p> <p>What has been written?</p> <p>What date?</p> <p>Which professional and their grade recorded it?</p> <p>Any care plans created?</p> <p>Any referrals?</p> | |
| <p>Nursing</p> <p>What has been written?</p> <p>What date?</p> <p>What is the nurses role/ banding?</p> <p>Any care plans created?</p> <p>Any referrals?</p> | |

| | |
|--|--|
| <p>Occupational Therapist</p> <p>What has been written?</p> <p>What date?</p> <p>What is their role/ grade?</p> <p>Any care plans created?</p> <p>Any referrals?</p> | |
| <p>Dietician</p> <p>What has been written?</p> <p>What date?</p> <p>What is their role/ grade?</p> <p>Any care plans created?</p> <p>Any referrals?</p> | |
| <p>Any other professional?</p> <p>What has been written?</p> <p>What date?</p> <p>What is their role/ grade?</p> <p>Any care plans created?</p> <p>Any referrals?</p> | |

Data extraction: MDT patient records. Version 1, 5.7.2017

Appendix 31: Direct observation data extraction tool

Direct observation: Patient care

Date: **Time:** **Patient Identifier:**
Questions to answer before the observation period commences

Ward nursing staff levels on the day of data collection (record n RN:NA from ward whiteboard)

General Ward environment (busyness, noise, people)

Patient's environment (bay, side room, other patients present, other people present, visitors?)

Patient position (in bed, in chair, standing)

Oral fluids present (if yes, note position, type of drinks, type of cup, any drinking aids, how full)

Information above the patient's bed (if yes: what? Oral fluid preferences, dementia symbol, preferred name, other preferences?)

IV fluids in progress?

Are there any other factors of relevance to oral fluid intake or person-centred care?

If yes: please record

Quality of Interaction: Ratings

Positive social (+s) Interactions, which may be expected to make the service user feel valued, cared about or respected as a person.

Positive Care (+c) Interactions, which may be expected to make the service user feel safe, secure, cared for or informed as a patient.

Neutral (N) Interactions which would not be expected to impact on the feelings of the service user, which they would be indifferent to or which they may barely notice.

Negative protective (-p) Interactions that may make the service user feel rushed, misunderstood, frustrated or poorly informed as a patient.

Negative restrictive (-r) Interactions which may leave the service user feeling ignored, devalued or humiliated as a person.

Date:

Patient Identifier:

Patient

Demographics

Age:

Ethnicity:

Date admitted to hospital:

Date admitted to this ward:

Reason for admission:

From home/ care home:

Language:

Marriage status:

NOK related or friend:

Type of dementia:

Any other relevant information:

Date:

Patient Identifier:

| Time: Start and end | Interaction? Yes/No | With who? | QUIS rating | Field Notes |
|---------------------------|------------------------|--------------|----------------|-------------|
| | | | | |
| | | | | |
| | | | | |
| | | | | |

Appendix 32: Table of communication strategies and barriers to providing hydration care to OPLWD in acute hospital wards

| Sub-theme | Strategy | Barrier |
|---|--|--|
| Communication between staff and OPLWD | <ul style="list-style-type: none"> • Verbal encouragement: reminding, prompting, orientate the person • Non-verbal communication: speak directly to the OPLWD, make eye contact, smile, get to the OPLWD's eye level, provide visual prompt • Promote hydration alongside other tasks • Providing enough time • Combine communication with action | <ul style="list-style-type: none"> • Reliance on verbal communication: no drink menu • Communication challenges: hearing impairment, visual impairment, discomfort, anxiety, tiredness, English as a second language • Not asking the OPLWD their choice • Brief, task-focussed communication |
| Communication between staff | <ul style="list-style-type: none"> • Clinical documentation: of the fluid target, utilising fluid balance charts, daily nursing entries about a person's hydration care • Healthcare staff supporting the host • Verbal handovers • Communication on boards above an OPLWD's bed | <ul style="list-style-type: none"> • Clinical documentation: no hydration care plan, no clear target for fluid intake documented, discontinuing fluid balance charts with no rationale documented, inconsistent or inaccurate use of fluid balance charts, entries about hydration are not very specific, the staff providing drinks are not documenting in the clinical records, the staff spending the most time with OPLWD are not documenting in the clinical records, medical staff do not often document about hydration • Advice from verbal handovers is not acted on or not trusted by staff receiving the information • There is a lack of information on the bed boards or the information is not acknowledged |
| Communication between staff and carers | <ul style="list-style-type: none"> • Hospital carers policy: advises to identify carers, discuss their preferred level of involvement and use a 'carers card' • Carers visiting wards • Asking carers about their relatives preference | <ul style="list-style-type: none"> • Staff not interacting with carers when they are present • Staff not including carers n discussions about the OPLWDs care or finding out their preferences • Staff not documenting the information provided by carers |

| | | |
|--|---|--|
| | <ul style="list-style-type: none"> • Carers advocating for the OPLWD • Staff making time to meet with carers and documenting the information gained from carers about the OPLWD | <ul style="list-style-type: none"> • Staff asking for information which is only specific to their role and therefore excludes information about hydration |
|--|---|--|

Appendix 33: Table of action strategies and barriers to providing hydration care to OPLWD in acute hospital wards

| Sub-theme | Strategy | Barrier |
|--|---|--|
| Providing direct support with hydration care to the OPLWD | <ul style="list-style-type: none"> • Action alongside communication • Setting up hydration: finding out the person's preferences, pour drinks, take drinks to the person, pass them a drink, leave drinks within reach, place a drink into the person's hand, hold a drink to their lips, reposition the OPLWD to aid intake • Monitoring: monitor intake, observe the person's response to drinks, assess the level of support required • Provide drinks when carers are present • Facilitate hydration when engaging in other care tasks | <ul style="list-style-type: none"> • Not providing any actions that support hydration when drinks are provided or offering support in an untimely manner (and drinks are cold) • Not providing drinks when carers are present • Not assessing the level of support an OPLWD requires or desires |
| Leadership | <ul style="list-style-type: none"> • Leadership visibly supporting hydration care • Leaders auditing hydration care and documentation | <ul style="list-style-type: none"> • No visible hydration leadership • Minimal interactions between leaders and OPLWD • Leaders not auditing hydration care |
| Associated aspects of care | <ul style="list-style-type: none"> • Promote oral hygiene | |

Appendix 34: Table of resource strategies and barriers to providing hydration care to OPLWD in acute hospital wards

| Sub-theme | Strategy | Barrier |
|---|--|--|
| Identifying OPLWD | <ul style="list-style-type: none"> • Use of a symbol above the bed to identify OPLWD | <ul style="list-style-type: none"> • Not using the identification symbols • Providing staff with the knowledge about what the symbols mean |
| A documentation system to record information about the OPLWD | <ul style="list-style-type: none"> • Using a document to record an OPLWD's likes, dislikes and other important information • Asking carers to contribute to the document | <ul style="list-style-type: none"> • Not utilising the documentation system to record information about a person • Staff not being aware of the documentation systems or where to locate them • Staff not knowing how to or not feeling empowered to access the information to complete the documentation |
| Identifying people that require additional help with eating and drinking | <ul style="list-style-type: none"> • Using red cups and red trays to identify people that require additional help with eating and drinking • Developing projects to increase the use of available resources | <ul style="list-style-type: none"> • Not utilising the red cup and red tray system • Staff not knowing how to utilise the system |
| Choices and availability | <ul style="list-style-type: none"> • Water jugs being present • Providing a choice of drinks that staff and OPLWD are aware of • Providing a choice of cups and mugs • Having access to drinks | <ul style="list-style-type: none"> • Water jug not being present • Water jugs being left out of reach • Limited choices available • Limited choices offered even if they are available • Inconsistent information about what is available and staff awareness about what is available • Lack of access to kitchens • Not offering a choice of mug or cup • Inappropriate cups provided for the OPLWD's functional ability • Lack of resources to make drinks outside of the routine drink round • Hosts and healthcare staff sticking to routines rigidly and not providing drinks outside these times |

Appendix 35: Table of environmental strategies and barriers to providing hydration care to OPLWD in a hospital ward

| Sub-theme | Strategy | Barrier |
|------------------------------------|--|--|
| <p>Social environment</p> | <ul style="list-style-type: none"> • Staff facilitating a social environment: spending more time with the OPLWD, engaging the person in occupation and activity, engaging with the OPLWD's psychological needs and emotions including managing pain, walking with the OPLWD • Having and using a communal dining table • The OPLWD having personal items present • Having and using activities to provide occupation on the ward • Providing drinks as a therapeutic strategy | <ul style="list-style-type: none"> • Staff approach: ignoring the OPLWD's psychological or emotional needs, not treating pain in a timely way, safety-orientated, task-orientated, only dealing with the person's psychological or emotional needs in the immediate moment • OPLWD experience a lack of social engagement: there are limited opportunities for interact with staff beyond direct care, OPLWD do not regularly interact with other patients • Not having communal dining tables on all wards • Not using communal dining tables when they are available • There are limited opportunities for the OPLWD to engage in occupation and activities • The OPLWD experiencing isolation • The OPLWD sleeping a lot • The OPLWD being distressed • The wards being busy and noisy places • |
| <p>Physical environment</p> | <ul style="list-style-type: none"> • Staff using the boards above the person's bed to document their name • Using the physical environment to display information and education about hydration for OPLWD | <ul style="list-style-type: none"> • The environment not always being conducive to eating or drinking • Not using the environment to display information and education about hydration for OPLWD • Having no access to a place where a person can independently make a drink • Not being able to leave the immediate environment easily • Staff having a lack of control over the environment |