An exploration of relationship centred approaches for the care of patients and their family carers with delirium superimposed on dementia in hospital settings: an appreciative inquiry

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Contents

Abstract

Background - There are approximately 982,000 people living with dementia in the UK. People with dementia admitted to hospital are at risk of developing delirium. Patients with delirium superimposed on dementia (DSD) have higher mortality rates, longer hospital stays and further cognitive loss. The role of family is often recommended as a resource to inform and support how patients with dementia's needs are understood. However, little is known about how people living with dementia admitted to hospital are supported when they experience delirium and what interventions, involving healthcare professionals and staff, may improve care and experience.

Methods - The study involved three phases of data collection. A scoping review of studies designed to explore what supportive interventions, involving family carers and healthcare professionals when providing care for patients with DSD in hospital, were completed to identify the gaps in the evidence. Findings from the review provided the context and questions for the primary data collection. A modified 4D Cycle of Appreciative Inquiry (AI) structured the research approach and data collection working with participants in one district general hospital in England. Observation in seven ward environments, and semi-structured interviews using a blended approach of storytelling and emotional touchpoints were used to understand how people with, or at risk of DSD, received care and how staff's responses, activities and management of the environment affected patient and family outcomes. Ethical approval reference number: 280075/22/EE/0144.

Results - The scoping review included fifteen studies that focused on educational, and system change to improve the care of people with DSD. Family involvement in these studies ranged from enabling staff's baseline assessment of delirium, commenting on different resources and measures designed to support their involvement in care, simulating their presence for the person with DSD and volunteer involvement as a proxy for family care. The evidence of effectiveness was mixed. Interventions to support personalised care and give family carers and staff confidence were positively evaluated. There was very little evidence of what enabled family carers to participate in care and work with staff despite the studies highlighting the importance of their involvement. Benefits to patients over time were unclear.

Seventy-four people with DSD across seven wards were observed. Interactions with staff were variable with noticeable differences between how qualified and unqualified staff anticipated or responded to people with DSD symptoms. There was evidence of how family members' knowledge of the patient could directly inform care practices. There were few observed opportunities for family involvement. Thirteen interviews with family carers (3), nursing staff (3), healthcare assistants (4) and other staff groups (3). Themes that were identified as likely to influence and improve the care and understanding of supporting patients with DSD included: education, addressing cultural influences, understanding of DSD, environmental challenges and relational care. The findings supported a focus that builds on what currently works well and how this may be developed across all healthcare systems to support patients with DSD.

Conclusions - Delirium superimposed on dementia (DSD) is often conflated with dementia and/or being old by healthcare professionals and families. Distinguishing between delirium and dementia can be challenging. The review findings provide evidence for clinical practice when selecting existing interventions and approaches involving family in supporting patients with delirium superimposed on dementia (DSD).

Family with prior experience and practitioners with personal experience, or in regular contact with patients, were better equipped to recognise symptoms and respond.

The evidence identifies the potential of family to mitigate the risk of delirium and improve patient outcomes.

Appreciative inquiry provided a structure for family carers and healthcare professionals to recognise and share good practice. The approach supported small, effective, cultural and practical changes aligned with the needs of patients with DSD and their family carers, and the systems of care related to DSD within the hospital setting.

Additional work is needed to focus on specific areas, such as interventions, education and training to support patients with DSD, that are developed in partnership with family carers, which account for time constraints and competing demands of a busy healthcare environment.

Acknowledgements

I had little insight into the academic and emotional challenges that this journey would bring when I started. This dissertation has taken every ounce of my resilience, humility, confidence, courage, commitment and sense of self to complete, and I am genuinely thankful for the opportunities that this project has provided. I have enjoyed learning to become a researcher, the people I have met, changes that it has supported me to bring to my practice, the confidence I have developed, and the connections and experiences that I have made along the way.

I would like to take this opportunity to express my wholehearted appreciation to everyone who has given me their support and assistance. First and foremost, my thanks go to my supervisors, Professor Claire Goodman and Dr Jennifer Lynch. Both have been so generous with their time and knowledge, proposing prompt and useful advice and questions to stimulate and test my thinking to improve my work beyond recognition. I must also acknowledge the emotional support that they have given me through the height of the pandemic, showing a deep understanding of the impact this could have on both my personal studies and professional life. Thank you to them both also for developing my confidence and thinking and helping me to grow in my professional role. And thank you to them both most recently during a very difficult time in my personal life, their understanding and support has meant so much. I would like to thank my Trust for supporting me in funding my studies, thank you for believing in me.

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Most importantly, I would like to acknowledge the contributions of the research participants and the Trust research team, and ward managers and clinical leads who enabled the process. They were endlessly generous with their time and experiences and welcomed me into the wards, and their homes. I hope that they will continue to be appreciative for many years to come. The participants' stories and ideas, the scoping review and the insights gathered from the observation work have informed and shaped this work and are key to this dissertation. I will cherish the memories of the interviews, using emotional touchpoints, and appreciate the trust and confidence the participants had in me to listen to their stories, the warm smiles and hugs of thanks when the interviews had finished, many of whom have since approached me following this with thanks, suggesting it was the first time they had the opportunity to share their experience. I can never thank them enough for their part in this study and genuinely hope that I have done them justice. I would like to thank my family and friends. Most of my dear friends and my extremely large family, mostly will go unnamed, but they know who they are and the part that they have played in getting me through this difficult journey. Special mention goes to my Mum who made me believe that I was capable of this and has offered support and understanding throughout, and to work colleagues who have provided encouragement. My friend Mandy who has provided kind words and encouragement, and my dog Winnie who has spent many hours beside me on the sofa, or up at the table on her own two chairs. Lastly, my husband Anthony and my daughter Kayleigh, who have been there for me every step of the way, never questioning my ability to do this and not being cross when I have been studying again. Regardless of all the useful advice, insightful ideas and critique that I have received throughout the conception and completion of this thesis, I bear the sole responsibility for any mistakes that remain.

Dedication

I dedicate this dissertation to my Dad, to whom his memory is what drives me to be a good nurse and to make him proud. To my Mum for understanding my passion, drive and commitment in a role that requires such heartfelt dedication, and to all those patients with dementia I have cared for. I hope that I have gone some way to shine a light on your experiences and to your families who are often so courageous, compassionate and kind.

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Abbreviations

AD	Alzheimer’s Disease
AI	Appreciative Inquiry
ARD	Alcohol Related Dementia
BIA	Best Interest Assessor
BGS	British Geriatric Society
CNS	Clinical nurse specialist
CQC	Care Quality Commission
DCM	Dementia Care Mapping
DoLS	Deprivation of Liberty Safeguard
DSD	Delirium Superimposed on Dementia
END-DSD	Early Nurse Detection of delirium superimposed on dementia
FAM-CAM	Family confusion assessment method
FAM-FCC	Family focused function care intervention
FC	Family carer healthcare professional
HK	Housekeeper
IRAS	Integrated research application system
JBI	Joanna Briggs Institute
MCA	Mental capacity assessment
MeSH	Medical subject heading
MBDRS	Modified blessed dementia rating scale
MMSE	Mini mental state examination
NHS	National Health Service

PLWD	Person living with dementia
QOL-AD	Quality of Life in Alzheimer’s Disease
PRISMA	Preferred reporting items systematic reviews and meta-analysis
RN	Registered nurse
RCT	Randomised control train
SFP	Simulated family presence
VDCC	Volunteer dementia and delirium care
WHO	World Health Organisation

Glossary

Acute Hospital	A healthcare facility that focuses on providing short-term medical care for patients with urgent medical conditions.
Acute care	Care provided in hospital for brief, sudden and severe illness.
Antipsychotic medications	Drugs that are used to treat severe agitation, distress or aggression caused by psychotic symptoms such as hallucinations or delusions.
Delirium	Delirium is a change in a person’s mental state that happens suddenly over 1-2 days. It’s often the first sign that someone is becoming unwell. Delirium can look different from one person to the next. Some people may become agitated or distressed while others are drowsy or withdrawn. The common feature to everyone who has delirium is that they become less responsive or alert to things happening around them.
Delirium Superimposed on Dementia (DSD)	Occurs when delirium develops in a patient with dementia. It can happen in up to 49% of patients during hospitalisation.
Distressed behaviours	Actions, words or behaviours exhibited by a person living with dementia that may be a sign of distress, or distress including shouting, crying, calling out, restlessness and pacing.
Emotional Touchpoints	A touchpoint is ‘any moment where a user interacts in some way with the service’ (NHS Institute Innovation and Improvement, 2009). Examples could be arriving on the ward, talking with a nurse, waking up after surgery, mealtimes, being discharged, etc. Emotional touchpoints ‘are the moments where the person recalls being touched

	emotionally (feelings) or cognitively (deep and lasting memories)’.
Family Carer	Someone who takes care of a person who is young, old, ill, or disabled (having an illness, injury, or condition that makes it difficult for them to do some things that other people do), either as a family member or friend, or as a job.
Health Care Professionals	Someone who works in the medical profession, for example, a doctor or a nurse.
Health Care Support Workers	Someone who works closely with registered healthcare professionals, including nurses and doctors, supporting them, and helping patients on their health journey.
National Institute for Health and Care Excellence (NICE)	A public body in England and Wales that is part of the government department responsible for health and social care. NICE issues guidance on clinical practice.
The Kirkpatrick model	A four-level model for evaluating training that highlights the different outcomes that can be achieved from training. The four levels are: (1) learners’ reaction, (2) learners’ knowledge, (3) leaners’ behaviour and (4) outcomes and results.
World Health Organisation	An agency of the United Nations, the WHO has a responsibility for international public health.

Chapter 1 - Introduction

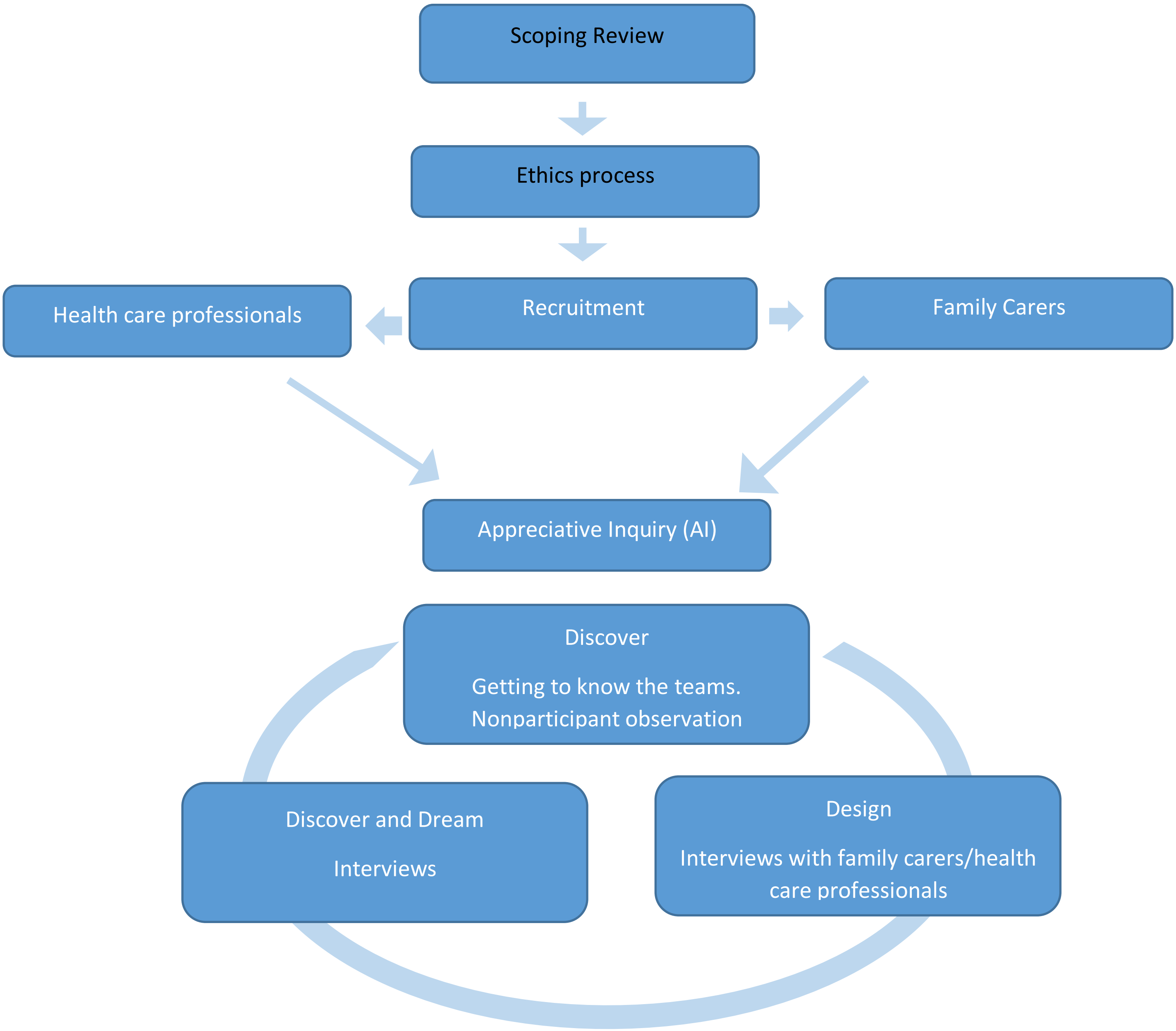
“Kindness can transform someone’s dark moment with a blaze of light. You’ll never know how much your caring matters. Make a difference for another day”.

Source: Often attributed to American writer and motivational speaker Amy Leigh Mercree.

This thesis explores good practice in caring for patients with delirium superimposed on dementia (DSD) and their family carers in hospital. An appreciative lens was applied to a multi-method study design which was delivered in two phases (Figure 1). Phase 1 was a scoping review of the evidence to identify what was already known about supportive interventions, involving family carers of patients with DSD in hospital. Phase 2 used the Phase 1 findings to inform a ‘4D’ Appreciative Inquiry (AI) intervention study, using the Discover and Dream stages, that sought to understand how patients with DSD are supported in hospital and how healthcare professionals may work together with family carers through relationship centred practice.

This chapter will provide a short introduction to my personal values and beliefs influencing my worldview and influencing my research choices in this study. The chapter will conclude with an outline of the structure of the thesis.

Figure 1 - Study Design Diagram



My personal worldview

"Strive not to be a success but rather to be of value" [1]

-- (Albert Einstein)

I have been a registered nurse for 28 years, with my clinical experience predominantly in the acute hospital setting. I remember wanting to be a nurse from my infant school days and, being the oldest of 6 children, I had plenty of practice caring for others. My ambition to be a nurse did not come from having family members in the field but just a moral and personal aspect of myself. At the age of 24 I became my Nan's carer when she developed dementia after her husband died suddenly. They had lived a very sheltered life and, after he died she declined rapidly. Moving in with my Nan to care for her at a relatively young age, and having a daughter of the age of 3, did not come without its challenges but there were some wonderful moments of connectedness, humour, reciprocity, empathy and understanding. The reciprocity I encountered from this personal experience strengthened my determination to gain the qualifications I needed to enter nursing and to have a career that I would be proud to have. After qualifying in 1996, my first post as a Registered Nurse (RN) was on a Care of the Elderly ward. I loved that job and remained on that ward for 4 years. During that time, I cared for many patients with Dementia but did not have any understanding of delirium; I guess I just thought it was dementia. While on this ward I was told, "Don't stay on this ward, you won't develop or learn, elderly care is boring". While I did listen to this and went onto a secondment role in Oncology/Haematology, and then 48-hour admissions in my early years of nursing, they couldn't have been more wrong.

I became interested in delirium, and how it impacts on dementia, while working on the admissions ward. On this ward, the emphasis was on a quick turnaround for discharge. I grew attached to some patients and would worry discharge home was not in their best interest given the nature of their progression and level of social/family support. Now the phrase we use is "home is best", and I began to understand that delirium may

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[1] 1 The above quote is often attributed to Albert Einstein, but its exact source is not well-documented. It is possible that this quote encapsulates his philosophy rather than being a direct quotation from his written works or speeches

take some time to pass, but our understanding of it and how it was communicated to each other and to families really mattered.

On a personal level, my wonderful Dad who died in 2003 from Cholangiocarcinoma (cancer of the bile duct) had terminal delirium at the end of life. Despite being in hospice care for those last few days and having a rapid change of alertness, confusion and conscious level the day before he died, I did not feel the knowledge of delirium, or how I was prepared to witness what I saw, and experience were informed or communicated to me. This strengthened even more the work I do and how I want to support families. The memory of my Dad during those last few hours and the support I had will remain with me.

More recently, my 37-year-old daughter became suddenly unwell, and delirium was the first indicator something was seriously wrong. She was then diagnosed with sepsis and many other complications. Witnessing this and helping her to come to terms with what happened, has drawn on all my professional knowledge and insight as both a nurse and a family carer.

Furthermore, the inequitable care, and the general negative status of older peoples' nursing, including dementia care, has sparked my passion for improving the care and recognition of DSD and my career has remained in this field. My many years as a ward manager has provided me with the opportunity to focus on humanising dementia care, providing staff with opportunities for learning, being a role model for best practice and to encourage staff to appreciate and to be proud of the care that is delivered despite the many barriers and challenges we may face. Now in my role as Admiral Nurse/Dementia Clinical Nurse Specialist, I have been fortunate to have been involved in strategic, organisational and clinical improvements at a Trust Board level that I believe has fundamentally influenced and raised awareness of the understanding of dementia and delirium care. Recently when I was introduced by our Director of Nursing to a visitor from outside the Trust, she said “Caroline does a great job of reminding us all how to care for our patients with dementia and delirium”.

My professional roles have included being a nurse, leader, manager, educator, practice developer and novice researcher. I reflect on and appreciate caring and supportive relationships and teamwork. While I miss the role of the ward manager, and the connectedness it brought to discuss ideas with other team members, I'm appreciative of being in an autonomous role, one that I am most proud of. I am inherently humanist, and I search for and engage in projects and new incentives, ways to raise the profile of dementia to the forefront of everyone's minds.

Within my role as a Dementia CNS, I see a large part of it as a supporter, enabler, role model and friend for my colleagues, both in hospital and in my volunteering role for colleagues and family carers and people living with dementia outside of the hospital, to provide them with the resources and support to enable them to care. I highly value the reciprocal nature of caring, and the pleasure that a good caring experience can provide. My interest in how we form relationships in healthcare, the impact of relational care and how person-centred care and relational care are interlinked. My motivation is not only a human element of relieving suffering, but also the desire to make a difference and the personal belief that after 29 years as a qualified nurse I still have the courage, compassion and commitment to do this.

My previous research has included exploring the views of the experiences of domestic staff and porters when working alongside patients with dementia in hospital (Ashton and Manthorpe, 2019) and the end-of-life care for patients with dementia in hospital. Understanding how to provide care for patients with dementia at the end of their life and addressing concerns with other colleagues around ethical decision making in, for example decision making and supporting colleagues and families in regards to the appropriateness of artificial nutrition versus risk feeding is instrumental to my role, and has strengthened my desire to also consider how these fit with the consequences of terminal delirium at the end of life.

In the last decade, I have had a growing concern that dementia services, though focusing on processes and outcomes to drive improvements, are unconsciously losing the holistic approach of nursing when caring for a patient with DSD and their family. This is exampled in respect to the drive for single rooms within the new hospital programmes. It is the combination of my interest in delirium superimposed on dementia; a desire to redress the balance between the organisational, task driven focus of care and providing holistic, person-centred care to people with DSD; also considering the needs of the healthcare team and the family carer in the caring dynamic, that has led to me researching relationship centred dementia and delirium care in hospital.

Research Motivation

The primary motivation for this study emerged from five sources. Firstly, my own personal experience, discussed earlier. Secondly, questions posed by a family carer of an 86-year-old gentleman with vascular dementia, admitted to hospital during the first wave of the pandemic, “If I had been allowed to visit, would my father’s delirium have got as bad as it did?” and “Were there no alternatives to manage his anxiety other than sedation?”. Thirdly, and shortly afterwards being deployed to manage an end-of-life care COVID-19 ward and witnessing the significant distress at the end of life for those patients living with dementia experiencing terminal delirium.

Fourthly, my work as an Admiral Nurse/Dementia CNS, in which I constantly strive to make a difference in the lives of people affected by dementia. Witnessing the impact on patients with dementia that delirium may have, the distress experienced by family carers and staff who may find this area of nursing care a challenge, and for whom I wish to demonstrate how important those little acts of kindness are and the difference they can make. And lastly, noticing distress and recognising how a compassionate approach to care, humanising what is often task focused care driven by the medical model, highlighting an under researched area of dementia and delirium care a significant priority.

The approach of AI adopted in this study fits with my values and work as a practitioner. Within this world view the researcher is seen as part of the study rather than apart from it. This study therefore required me to encompass reflexivity. Pope (1999) suggests that sharing personal and intellectual influences at the outset of any research enhances its credibility by enabling the reader to judge this in the context of findings. This section explores personal aspects that relate to the present study.

My professional background is firstly that of a nurse, then educator, researcher, practice developer and role model. I have worked as a registered nurse for many years, with a background in elderly and palliative care, with eight years’ experience in a specialist field. My current role, whilst strategic, requires a combination of bedside nursing care, leadership, education and family carer and staff support. Therefore, I have been able to draw on a wide range of knowledge to inform this study.

In my personal life, reflecting on times when caring for a relative, I have been appreciative of the level of kindness and embracing a relationship centred approach to care.

In my professional life, I am committed to a philosophy of caring that includes developing a vision with the team, valuing each other in a way that builds on people’s strengths, working “alongside”, “with” and “for” people, rather than “on” them, having the courage to defend what I believe in and is possible, and supporting others to do this.

My style of working is evidenced-based, relationship-centred, appreciative and has foundations in action research. My previous research experience has explored how domestic staff and porters (an often overlooked team within the wider NHS organisation) can contribute in supporting patients living with dementia in the hospital setting and how compassion, relationship centred working and teamwork support this (Ashton & Manthorpe, 2019). An approach to research that supports working with people to uncover the knowledge used in practice was necessary for this study.

I also consider the enormous pleasure and pride I have experienced over the years in caring for and about others and being cared for myself. This belief is the reciprocity that exists in the caring relationship has drawn me to the theory of relationship-centred care. In summary, my beliefs and values that stem from my experience and influence the study and include:

- Considering the needs of staff, patients and families in the care-giving relationship.
- Valuing learning that is appreciative, includes examining core beliefs and challenges assumptions.
- Recognising the importance of a shared vision to the process of change.
- Acknowledging that knowledge and power need to be shared.
- Provide nursing care that includes the fundamental aspects of care which embraces the values of the 6Cs: Care, Competence, Communication, Courage, Commitment and Compassion.

- Exploring what is important to the person within the caring relationship.

Having defined the beliefs and values fundamental in my approach to this study, I now briefly describe the background to this study and key considerations in setting it up.

Aims and Objectives

This thesis considers how delirium superimposed on dementia is understood in a hospital setting and how relationships between healthcare professionals and family carers can influence the patient's outcome and fundamentals of care. A particular focus on what already is working well but not ignoring areas that need further attention.

The overall aim of the study was to understand how strategies likely to promote closer working relationships between hospital staff, family carers and people with dementia in hospital and could help to avoid or reduce the impact of delirium.

The objectives of the study were:

➢ To determine the scope of everyday delirium care that people living with dementia experience in hospital.

➢ To understand what family carers of people living with dementia perceive as 'good' dementia and delirium care in hospital.

➢ To understand what the experience and perspectives are of family carers who provide support for patients with delirium and dementia.

➢ To understand staff's experiences of DSD, what factors influence patient care and family carer relationships.

Background

Delirium Superimposed on Dementia (DSD)

Delirium Superimposed on Dementia (DSD) is a highly prevalent, yet difficult to identify condition experienced by older people admitted to acute care hospitals. Its symptoms may be missed or misunderstood over time. Delirium is an acute and severe disturbance in cognition and attention that is most often seen in persons aged 65 years and older (Inouye et al., 2014; Oh et al., 2017). The term confusion may be more widely used by clinicians or others associating the delirium with dementia. The estimated prevalence of DSD ranges from 40% to 89% in older persons in hospital. One systematic review identified that the pooled prevalence of DSD was 48.9% with the highest prevalence found in the Americas and Orthopaedic wards (Han et al., 2022).

Delirium and Dementia have a complex inter-relationship (Fong and Inouye, 2022). Individuals who develop delirium have a higher risk of developing dementia than the wider population (Fong et al., 2015; Richardson et al., 2021). Fong and Inouye, 2022, suggest "whether delirium simply serves to unmask unrecognized dementia or an overlap in the pathophysiology of delirium and dementia initiates or accelerates neurodegeneration, remains unclear" (pg. 580).

Cognitive impairment and dementia are independent risk factors for developing delirium (Fong and Inouye, 2022).

Evidence indicates that people who have dementia and develop delirium have poorer outcomes, longer lengths of hospital stay, greater cognitive and functional decline, and a higher risk of institutionalisation and mortality than hospitalised patients with dementia who don't develop delirium (Han et al., 2022).

Delirium specific prevention strategies, cognition champions, Cogchamps, (Travers, 2018), Hospital Elder Life Programme (HELP), (Inouye et al., 1999), Software Engine for the Assessment and Optimisation of drug and non-drug Therapy in Older persons (SENATOR), (Abraha et al., 2015) have consistently been shown to be successful in reducing the incidence of delirium and reduction in adverse outcomes, such as falls, cognitive and functional decline, readmissions and healthcare costs (Hshieh et al., 2018, Inouye et al., 2000). These findings suggest that prevention strategies may also be useful in ameliorating the effect of delirium on the cognitive trajectory of dementia (Fong and Inouye, 2022).

Dementia

Dementia is an umbrella term that refers to a range of progressive neurodegenerative conditions for which there is no cure. The numbers of those diagnosed with dementia are growing rapidly with a worldwide prevalence of 55 million, projected to increase to 139 million by 2050 (Alzheimer's disease International, 2021), with over 60% living in low and middle-income countries. Dementia is currently the 7th leading cause of death in the world and one of the major causes of disability and dependency among older people (WHO, 2024). In the UK data from the Office for National Statistics, the National Records of Scotland and Northern Ireland Statistics and Regency Agency have confirmed that dementia remained the UK's biggest killer in 2023, claiming over 75,000 deaths.

There are many different types of dementia, the most common being Alzheimer's disease. Symptoms of dementia often include memory loss, confusion, speech and language impairment, and problems with tasks of everyday living such as dressing and cooking.

Responsive behaviours that may be experienced by those with dementia, often because of under or over stimulation, may present as irritation, wandering and calling out repeatedly (Cohen-Mansfield, 2001; James & Jackman, 2017; James, 2024). This cluster of symptoms can challenge and transform relationships with others. People living with dementia may experience loss of independence thus becoming reliant on family members or professional carers to support them (Alzheimer's Research UK, 2023). As the condition progresses, personal care including bathing and assistance with using the toilet may be required. Caring for people with dementia can be both overwhelming and challenging (Conner's et al., 2020, Teahan et al., 2021, Yildizhan et al., 2019). Considering the pressure for both informal and formal carers it is important to investigate ways that positive and functional relationships between those with dementia and their supporters can be reinforced or enhanced (Alzheimer's Society, 2021, 2022, Chew et al., 2022, Holt Clemmensen et al., 2021). Improved relationships benefit the well-being of both the individual with dementia and those providing care by supporting and motivating caregivers (Dombestein et al., 2020) and building reciprocity between the person with dementia and their carer (Van Corven et al., 2022). Long-term institutional care often results from a breakdown in the relationship between carer and cared-for, driven by factors such as the increasing complexity and intensity of care needs, or the carer's own health challenges. Evidence suggests the need for a person-centred approach taking into consideration individual and contextual needs as well as the continuum and progressive nature of dementia care (Oliveira et al., 2024).

Delirium

Delirium has been recognised in medicine for over 2000 years. Hippocrates first described symptoms resembling delirium in his work "Aphorisms"[2] around 400BC. The term delirium is traced back to antiquity, and despite a wealth of research confirming it is extremely common, it can be challenging to diagnose (Mattison, 2020). As we now understand, he believed delirium was a symptom of an underlying condition. Hippocrates attributed it to an imbalance in the humors which included, blood, phlegm, yellow bile and black bile. Therefore, he saw it as a physical illness and one that resolved as the person got better. He observed, "when sleep puts an end to delirium, it is a good symptom (Adams, 1868). Despite many years of understanding, the ability to recognise, diagnose and provide care remains a challenge. In the nineteenth century, the approach was centred on identifying syndromes rather than making a precise diagnosis, with its prognostic and management considerations shaped by phenomenological principles. Not until the twentieth century was there a call for recovery from delirium, this was likely as a desire to identify a clear distinction from dementia (Adamis, 2007). Many conclude that delirium has a relationship with acute illnesses especially those associated with fever.

One of the most important barriers to the adequate treatment and medical and nursing intervention of delirium is that it is so commonly unrecognised or misdiagnosed. Philosophical theories have influenced definitions of delirium dependant on how we view the body, the psyche and its relationship, since this is a clinical condition that can

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[2] The term "aphorisms" is closely associated with **Hippocrates**, the ancient Greek physician often referred to as the "Father of Medicine." Around 400 BCE, Hippocrates compiled a series of concise statements or observations about medical practice and human health, which became known as the **Aphorisms of Hippocrates**. These aphorisms were foundational in the development of medical ethics and practice.

cause mental health issues. There is universal agreement about the seriousness of delirium and its poor prognosis, delirium may cause permanent mental disturbance after its immediate cause had resolved (Rockwood et al., 1999).

Delirium is defined as an "acute disturbance of consciousness and cognition that develops over a short course with fluctuating symptoms" (Roden & Simmons, 2014,pg 129). Delirium is also defined as a group of mental and behavioural problems alongside physical disease (Lipowski, 1991). Definitions generalise its transient, intermittent and proprietary nature (Berrios, 1981). It is unrivalled by any other condition in its ability to affect people across all clinical specialities and is not restricted to older people (O'Hanlon et al., 2014).

The prevalence of delirium in a hospital population can be used as a measurement of quality of care and safety of patients during hospitalisation (Fong et al., 2009). Although not always avoidable, evidence suggests that incident delirium can be avoided for some patients if suitable recognition and avoidance strategies are in place (Anderson, 2005; Cerejeira & Mukaetova-Ladinska, 2011). Intermittently, patients are essentially acutely agitated, however this is considerably less common than the hypoactive or quiet variant (Marcantonio, 2017, Robinson et al., 2011). For many patients there can be a mixed picture, with symptoms predominately of the hypoactive type and occasionally characterised by agitation. In a recent study, Lee et al. (2025) underscore the importance of affording neuropsychiatric disturbances associated with delirium independent clinical and research attention, paralleling the recognition long granted to those observed in dementia.

Delirium is an acute change in mental status and must be distinguished from dementia, which is characterised as a chronic condition with slower progression of brain failure. However, dementia and delirium often coexist because pre-existing cognitive failure is a risk factor for delirium (Mattison, 2020).

A systematic review identified multiple short delirium detection tools validated in research studies and implemented in routine care, but there has been little study outside research settings, the review found variability in tool completion rates and called for greater evidence of the value of their use in routine care (Penfold et al., 2023).

Clinical guidance on the management of delirium such as SIGN 157, (2019), Risk Reduction and management of delirium guidelines (pathway) (Appendix 1), recommend that if a patient develops delirium, and at discharge following an episode of delirium, appropriate information leaflets should be provided to the patient and family, staff should explain to family carers how they can support the person with delirium and care needs should be reviewed. Suggested strategies include ensuring the person has their glasses or hearing aids, provide familiar items from home such as photos or a favourite blanket, encourage regular eating and drinking, and assist to mobilise to the toilet.

Admission to hospital

The number of people with dementia in the United Kingdom (UK) is expected to rise to 1.6 million by 2040 (Royal College of Psychiatrists, 2011, 2024). In the UK, the last five years has seen an increase by 35% of unplanned hospital admissions for people with dementia, and up to one in four hospital beds reported to be occupied by someone with dementia (Abbott et al., 2022), occupying a total of 3.2 million bed days a year in the UK (DOH, 2015, 2020). In the UK, the number of people with dementia admitted to hospital every year increased by 93% from 210,000 in 2010/2011 to 405,000 in 2017/2018 (Alzheimer's Research UK, 2024).

Prevalence estimates for dementia in studies with robust methodology were 12.9-63.0%. Less than a third of studies screened for delirium or depression and therefore some subjects may have been misclassified as having dementia (Mukadam & Sampson, 2011). A report from the UK Alzheimer's Society "Fix Dementia Care Hospitals" (2016) illustrated the negative impacts, both physical and emotional, that inadequate care and management in hospitals can have on people with dementia and their families, and identified that once in hospital, people with dementia stay for twice as long as people without the condition (Alzheimer's Society, 2016). Torjesen (2020), reports figures show a big increase in emergency admissions for dementia patients, with existing dementia more than double the risk for COVID-19 admission.

Co-morbid conditions are common, and dementia is infrequently the primary cause of admission (Bunn et al., 2014). Consequently, dementia care may often be considered a low priority compared to the primary reason for admission but recognised as generating extra demands on staff time and resources (Moyle et al., 2011). Improving dementia care in general hospitals has been a policy priority for over ten years (Department of Health, 2006, 2015).

The Burden of Delirium Superimposed on Dementia in hospitalised older patients

As previously noted, dementia is a risk factor for delirium (Inouye et al., 2014). Hospitalised older people with a background of dementia have an increased risk of developing delirium but little is understood regarding the effect of delirium superimposed on dementia and the outcomes of these patients and the impact for carers/staff (Avelino-Silva et al., 2017).

Delirium is linked to poor outcomes in older PLWD, such as accelerated cognitive decline, increased functional dependence, increased risk of falls, extended length of stay, readmission to hospital, initialisation, loss of quality of life and mortality, compared to PLWD without delirium (Crocker et al., 2016; Fick et al., 2002; Fong et al., 2022; Han et al., 2022; Morandi et al., 2014, Morandi et al., 2020). Some older PLWD who have recovered from the incidence of delirium may recall the distress they experienced during the delirium episode (Morandi et al., 2015). While it may be difficult to truly appreciate, it is thought that the PLWD may continue to experience anxiety, fear and anger following the delirium experience and they may be fearful of Health Care Professionals (HCP) and may even believe they are going to be harmed (Morandi et al., 2015).

Detection of Delirium superimposed on Dementia

Prevention of delirium not only reduces the cost of delirium but also may decrease subsequent rates of dementia (Caplan et al., 2020).

Delirium detection is a significant concern in the context of dementia. Dementia may present similar symptoms to delirium, which make DSD difficult to recognise (Apold, 2018; Coyle et al., 2017; El Hussein et al., 2015). Failure to rapidly identify delirium can inhibit prompt treatment and can lead to persistent delirium. If symptoms of DSD persist it is unlikely the person will return to their cognitive baseline and are 2.69 times more likely to die than persons with resolved delirium (Fong et al., 2022; Han et al., 2022). Evidence suggest that unresolved symptoms of DSD increase the risk of mortality to more than double when compared to patients without dementia (Gordon et al., 2024, Mattison et al., 2020).

The 4-DSD, a tool to identify delirium in people with moderate to severe dementia was developed and use to detect delirium in a cohort of 134 patients in hospital within acute and rehabilitation wards (Morandi et al., 2015). The 4-DSD is a 4-item tool that ranges from 0-12. Item 1 measures alertness, item 2 altered function, item 3 attention, and item 4 acute change or fluctuation in mental status. A minority of the included patients were categorized with moderate dementia (Global Deterioration Scale (GDS) score of 5 (4%). Most of the patients fell within the moderate-severe stage with a GDS score ≤6 (77%); 19% were identified as severe, with a GDS score of 7. A 4-DSD cut off score ≥5 had a sensitivity of 80% and specificity of 80% with a positive predictive value (PPV) of 67% and a negative predictive value (NPV) of 89%. In the subgroup with moderate-severe dementia (n = 108), the sensitivity and the specificity were 79% and 82%, respectively, with a PPV and NPV of 62% and 92%. In the subgroup with severe dementia (n = 26), the sensitivity was 82% and the specificity 56% with a PPV of 78% and an NPV of 63% (Morandi et al, 2015). The availability of a specific tool to detect delirium in patients with moderate-severe dementia has important clinical and research implications, providing opportunities for all healthcare providers to improve their ability to identify it.

A systematic review and meta-analysis of the diagnostic accuracy of the Family Confusion Assessment method for the detection of delirium (Zhou et al., 2024) identified 7 studies with 483 dyads of patients (participants) and family caregivers. Pooled sensitivity and specificity were 0.74 (95% CI: 0.59, 0.86) and 0.91 (95% CI: 0.83, 0.95), respectively. The positive likelihood ratio was 8.27 (95% CI: 3.97, 17.25), and the negative likelihood ratio was 0.28 (95% CI: 0.16, 0.50). Settings impacted specificity (p = 0.02). Mailhot and her colleagues found that, compared to patients without dementia, Family Confusion Assessment Method (FAM-CAM) had a superior sensitivity in patients with dementia in the emergency department (Mailhot et al, 2020). Available evidence indicates that FAM-CAM exhibits moderate sensitivity and high specificity in older adults. A point prevalence study, Instenes et al, 2024 in surgical and non-surgical hospital wards screened 123 patients for delirium and found 27% tested positive for delirium on the 4AT test.

A more recent study, Sepulveda (2025) and colleagues examined screening time for delirium in dementia patients using the Spanish version of *Repérage Actif du Delirium Adapté à la Routine* (RADAR), in English recognising acute delirium as part of your routine. Of the 34 dementia patients included, 47.1% had delirium, and 83.3% had behavioural, mental or neurological disturbances that made diagnostic assessment difficult. The study identified nurses have a fundamental role in observing and recording changes in patients' mental state. However, they have limited time to perform numerous tasks, suggesting there is a need for simple screening instruments that are quick to undertake and adaptable to nurses' routine activities. The RADAR tool was developed to be used as a 6th vital sign assessed by nurses during the administration of medication and is based on patient observation. Earlier validation of the original version of the RADAR that included people with dementia (21%), the sensitivity and the specificity were 73 % and 67 % with respect to delirium according to the DSM-IV (Voyer et al, 2015).

The inter-relationship between delirium and dementia and the importance of delirium prevention

The inter-relationship between delirium and dementia is complex; delirium and dementia are two frequent causes of cognitive impairment among older adults and have a distinct, complex and interconnected relationship. Delirium is characterised by inattention, cognitive dysfunction and an altered level of consciousness, whereas dementia is an insidious, chronic and progressive loss of previously acquired cognitive ability (Fong and Inouye, 2022).

In the acute hospital, this may be difficult to identify and even harder to determine the cause. A recent case study below, using the Newcastle Model Framework (James, 2011)—a psychological framework, used in dementia care, particularly for understanding behaviours that staff find challenging—illustrates the issues and demonstrates how the symptoms of distress and behaviours are still difficult for staff to recognise. A key aspect of the model is its emphasis on therapeutic communication which can help reduce distress and improve interactions between caregivers and individuals with dementia.

Case Study

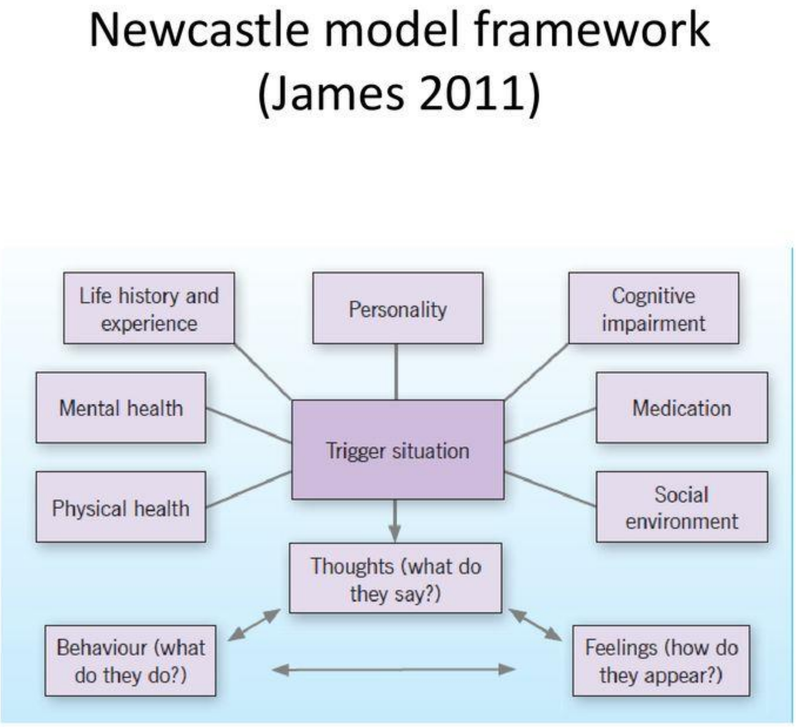
Mr Jones has a history of mixed dementia. He is 70 years old and living with his wife who is his main carer. Mr Jones also has a history of a complex neuro endocrine tumour which is currently stable. Mr Jones leads a quiet and sedentary life, he does not attend community groups, does not want to consider he has issues with cognition. Mrs Jones leads a relatively active life, has family and friends, and attends hobbies and interests outside of the home. There have been no social care needs to this point. Mr Jones attends to his personal care needs and can walk their dogs supervised.

On two days prior to hospital admission, Mr Jones was sitting quietly watching TV while Mrs Jones attended a local church group. Within an hour of her leaving the home, her neighbour called her, concerned Mr Jones was "wandering". The next two nights were very unsettled: Mr Jones was hallucinating, did not sleep and was very paranoid. 999 were called, despite no obvious cause of delirium, Mr Jones was admitted to hospital. On the ward, Mr Jones was identified as needing 1-1, was treated for a chest infection but blood markers were unremarkable. Mr Jones was medically fit for discharge after day 3 of admission. Throughout medical entries and nursing interventions, there was no documentation about delirium prevention or treatment strategies or discussion with family.

After day eight of admission (discharge had been delayed as Mrs Jones had the flu), a referral was sent to Dementia CNS for carer support and delirium care. Using the Newcastle Model (James & Stephenson 2001), a needs led biopsychosocial model that provides both a framework and process, developed by bringing together a variety of psychological models, (Beck 1976, Cohen-Mansfield 2000, Kitwood 1997). The framework provides contextual information about the person with dementia and specific details of the behaviour. Behaviour is often linked to dementia and just considered part of dementia without considering the meaning behind the behaviour such as unmet needs and delirium as a cause to behaviour.

Working alongside the staff and with the support of Mrs Jones, we enabled staff to consider that Mr Jones liked to walk around, he walks his dogs every day, this should not be labelled as wandering. Hallucinations were still present but not causing Mr Jones distress as far as we could tell. Mrs Jones asked if he could have some antipsychotic medications (her neighbour who had a family member with previous DSD suggested), but we discussed the harmful effects this could have. We looked at Mr Jones' spiritual and emotional needs, he thought his wife had gone out with another man and was going to divorce him. Strategies to support Mr Jones' spiritual needs going forward are being considered. Mr Jones recovered from delirium and went home with community support. Most importantly, it was important to try and prepare Mrs Jones for the eventuality delirium may develop again in the future and what to consider and look out for.

Figure 2: The Newcastle model framework, (James, 2011)



It is understood that delirium in individuals with dementia can accelerate further cognitive decline. Families often ask, “will my mum, my dad, get back to how they were before?”. Some families may also attribute hospital stay to further cognitive decline and delirium, often resulting in feelings of guilt and sadness, wishing they had not brought their loved one to hospital. While it is known that delirium prevention strategies can reduce the incidence of delirium and associated adverse outcomes, attention to delirium care in hospital remains variable, is under resourced and remains uncertain as to whose role this is anyway.

Understanding the pathophysiology of delirium and the connection between delirium and dementia might ultimately lead to additional treatments for both conditions.

Fong and Inouye (2022) in their review explore mechanisms that might be common to both delirium and dementia by reviewing evidence on shared biomarkers and discuss the importance of delirium recognition and prevention in people with dementia.

Some key points cited from their review are highlighted below:

- Delirium and dementia are frequent causes of cognitive impairment among older adults and have a distinct, complex and interconnected relationship.
- Delirium prevention strategies have been shown to reduce not only the incidence of delirium but also the incidence of adverse outcomes associated with delirium such as falls and functional decline.
- Adverse outcomes associated with delirium, such as the onset of dementia symptoms in individuals with preclinical dementia, and/or acceleration of cognitive decline in individuals with dementia might also be delayed by the implementation of delirium prevention strategies.
- Evidence regarding the association of systematic inflammatory and neuroinflammatory biomarkers with delirium is variable, possibly because of co-occurring dementia pathology or disruption of the blood-brain barrier.
- Alzheimer disease pathology, even prior to the onset of symptoms, might influence delirium risk, with potential mechanisms including neuroinflammation and gene-protein interactions with *APOE* E4 allele.
- Novel strategies, including proteomics, multi-omics, neuroimaging, transcranial magnetic stimulation and EEG, are beginning to reveal how changes in cerebral blood flow, spectral power and connectivity can be associated with delirium;

further work is needed to expand these findings to patients with delirium superimposed on dementia.

Building collaborative relationships with family carers of hospital inpatients with delirium superimposed on dementia

Delirium superimposed on dementia in hospitalised older persons is a distressing experience for family carers, who often provide up to 90% of the care in the community dwelling (Kasper et al., 2015). Carer distress is a significant concern, it can increase their risk of poor physical health and mental health which can negatively impact on their ability to care for their loved one in the community (Brodaty & Donkin 2022; Lwi et al., 2017).

Family carers when provided with the educational tools can assist with the early detection of DSD, due to their knowledge of the patients' baseline cognitive status (Carbone & Gugliucci, 2015; McKenzie and Joy, 2020), this may also help to alleviate distress in the family carer and reduce the older persons length of stay.

A relationship centred approach to care with family carers may lessen their distress and increase their role in DSD detection and management in acute care hospitals (Nolan et al., 2006). Despite this, there is a lack of qualitative research on family caregivers of hospitalised older persons with DSD (Fong et al., 2019, Grossi et al., 2020, Morandi et al., 2015; Yevchak, 2017).

Julian et al., (2022) exploring collaborative relationships with family carers of hospitalised older adults with DSD identified the following themes:

- Family caregivers found DSD to be an overwhelming experience.
- Family caregivers experienced distress, helplessness, shock and sadness at seeing the older person with DSD.
- Family caregivers felt they lacked information about DSD.
- Family caregivers play an important role in the detection and management of DSD.
- Family caregivers can be instrumental in identifying changes in cognition or health status.

- Family caregivers actively participated in strategies to manage symptoms of DSD.
- Family caregivers wanted to feel acknowledged, valued and respected.
- Family caregivers experience a power imbalance in their relationships with the healthcare team.

Many of these themes are identified throughout the following research. Julian's study concludes highlighting the need for training in relationship centred care and system wide education of DSD for family caregivers.

Delirium superimposed on dementia and COVID-19

Delirium disorder is a common "neurological complication of SARS-CoV-2 infection and associated with increased disease severity and mortality" (Bommarito et al., 2022, pg. 91). Cognitive impairment is a major risk factor for developing delirium during COVID-19, which as a result, increases the risk of subsequent neurological decline.

During the early phase of the pandemic, delirium was described as the most frequent neurological manifestation of the acute phase of COVID-19, affecting up to 65% of patients (Helms et al., 2020), and has been associated with an increased length of hospital stay and higher mortality (Mendes et al., 2021). A puzzling and noteworthy aspect were its manifestation as a very early or symptom onset, especially in older adults or individuals with cognitive impairment (Helms et al, 2020, Kennedy et al., 2020). This was also observed in my clinical practice. The latter fits with the emerging evidence of a relationship between COVID-19 and cognitive impairment, "strong and not unidirectional" (Bommarito et al., 2021). Patients with dementia are recognised as a greater risk of developing COVID-19 and often present with increased disease severity and risk of mortality (Tahira et al., 2021). During my experience in clinical practice, I witnessed both highly distressing symptoms of DSD presenting in patients with COVID-19, but I also cared for patients with DSD who tested positive for COVID-19 with no symptoms other than delirium.

Patients with dementia were particularly vulnerable during the COVID-19 pandemic while the pandemic delivered a challenge for all families. Increased age, commonly seen among dementia patients, is considered a predictor of poor outcome of hospitalization for COVID-19 patients. Research has highlighted that during the COVID-19 pandemic, for patients living with dementia admitted to hospital, delirium may have been the only/initial symptom of COVID-19 (Poloni et al., 2020).

A British study of 16,749 hospitalized patients with COVID-19 found a diagnosis of dementia also adds a risk factor unfavourable to the outcome with 39% higher risk of death (Leighton et al., 2022). Recent evidence identified that patients with dementia and delirium were four times more likely to die than those without (Zazzara, 2021,2024).

The British Geriatric Society (BGS) in 2020 published "Coronavirus: Managing delirium in confirmed and suspected cases. This was in response to BGS members highlighting the challenges they encountered in managing patients with delirium testing positive for COVID-19. The consensus was drawn up by experts from the European Delirium Association and Old Age Psychiatry Faculty (Royal College of Psychiatrists), highlighting agitation, may make management and delivery of care and reducing the risk of cross infection more challenging.

BGS suggest that delirium, the clinical expression of encephalopathy, is important in the context of COVID-19, because:

- Delirium may be a symptom at presentation and/or during management.
- Behavioural changes (commonly seen in delirium), particularly agitation, may make management and delivery of care and reducing the risk of cross infection more challenging.

Their recommendations follow two key themes:

1. Good general care, including prevention, early detection, and non-pharmacological management should be provided as systems allow.
2. The risk of harm to others may exceed risk of harm to self and this may necessitate earlier use of pharmacological treatments for potentially risky behaviour, however even in complex situations acknowledging the same rules of risk assessment and mental capacity apply.

For full recommendations, see Appendix 2.

The World Health Organisation (WHO) also provided guidance in caring for older people in quarantine, particularly pertinent to people living with dementia and /or experience delirium for those living in long term care facilities, other non-acute facilities and home care (WHO, 2020).

Family Carers and DSD

Utilizing family carers to assist with delirium care in acute hospital demonstrates improved outcomes supporting the need for patient and relationship centred care. Shrestha (2020) suggests family carers are a valuable resource in the recognition and management of delirium. Despite this, family carers' understanding, recognition and experience of supporting a person with DSD is often very limited (Julian et al., 2023, Morandi et al., 2015, Nitchingham et al., 2021, Paulson et al., 2016). Most studies exploring DSD currently focus on interventions to support healthcare staff.

Therefore, primary prevention with heightened importance on the role of non-pharmacological interventions and the elements of a closer working nurse/carer relationship in delirium prevention is essential.

Frameworks

As a result of the issues discussed above, the following recognised frameworks were used as a foundation to underpin the study.

- Relational Constructionism
- Person-Centred Care
- Relationship-Centred Care

The application of these frameworks is explored and discussed in relation to dementia and delirium care in hospital.

Conceptual Framework - Relational Constructionism

The epistemology in this study draws on the assumption that knowledge is not pre-existing or fixed or stable (Guba & Lincoln, 1989). Rather, knowledge is personal and participatory, evolving in the here and now of health systems (Jonsdottir et al., 2004) produced through practices, interactions and experiences.

The study uses a relational constructionism framework using an appreciative inquiry approach to data collection. In relational constructionism, assumptions about what exists are underpinned by concepts such as co-action and relational practice, which include people talking together, planning and discussing to make sense of what is happening and to embrace the notion of multiple realities (Jonsdottir et al., 2004). The relationship between the researcher and the participants is an equal one, where multiple, sometimes competing realities are documented but treated as of equal importance and relevance.

Introducing Relational Constructionism as the Epistemological Foundation of Appreciative Inquiry

This study adopts relational constructionism as the foundational worldview underpinning Appreciative Inquiry (AI). In doing so, it also traces how social constructionist thought has informed and evolved into a relational constructionist framework. The epistemological stance guiding this inquiry rejects the notion of knowledge as pre-existing, fixed, or stable. Instead, knowledge is understood as emergent produced through relational practices, interactions, and lived experiences. Consequently, a methodological approach that foregrounds relationships within the hospital setting—including those among staff, patients, and families—was deemed essential and is in parallel with my professional role.

Social Constructionism: A Foundational Worldview

Social constructionism provides the philosophical grounding for participatory methodologies such as action research and Appreciative Inquiry (Gergen, 1999; Gergen & Gergen, 2003). Central to this worldview is the idea that reality is not objectively given or naturally revealed but rather co-created through human interaction. Through dialogue, shared experiences, and cultural practices, individuals construct a reality that is experienced as subjectively meaningful and factual. This perspective challenges the notion of a singular, inevitable social reality, instead proposing that our world is continuously deconstructed and reconstructed across time and context.

Social constructionism resists hierarchical truth claims, advocating instead for pluralism and contextual understanding. It recognises that any attempt to describe, measure, or transform reality is inherently shaped by language, cultural expression, and relational dynamics.

Relational Constructionism: A Distinct Epistemological Stance

Emerging from the broader family of social constructionist and constructivist theories, relational constructionism offers a distinct perspective. While it inherits key ideas from radical constructivism—particularly the view that humans cannot directly access objective reality—it diverges by emphasising the relational conditions under which cognition and meaning-making occur. Ernest von Glasersfeld's radical constructivism (2013) posits that individuals construct knowledge through personal experience and cognitive structures. Relational constructionism builds on this by centring the relational and dialogic processes that shape understanding. This epistemological stance is threaded through my professional role, recognising that there are multiple realities, personal values and experiences that shape patient experiences, family carer experiences and staff satisfaction in care .

While social constructionism centres on how meaning is shaped through social interaction, relational constructionism extends this by incorporating material conditions and foregrounding the inherently relational nature of cognitive processes. Appreciative Inquiry (AI) is widely recognised as a methodology grounded in social constructionist philosophy (McNamee, 2002). Yet, social constructionism encompasses diverse strands, and AI discourses do not always make their philosophical assumptions explicit. Relational constructionism, however, can be understood as the philosophical heartbeat of AI.

The foundational links between AI and relational constructionism shape how AI is enacted, how questions are framed, and how change is imagined. These connections manifest in several keyways:

Relational constructionism posits that knowledge, meaning, and identity are emergent and relational rather than fixed. AI builds on this premise by viewing organisations as socially constructed through dialogue and shared narrative, thus fitting well with the research setting in this study. Appreciative conversations become generative spaces where new realities are collaboratively shaped. As Hosking and McNamee (2007) observe:

“Good questions are those that help to enlarge possible worlds and possible ways of being in relationships.”

Possibility-Focused, Not Deficit-Driven

Conventional problem-solving often assumes objective truths and seeks to rectify deficits. In contrast, AI—rooted in relational constructionism—shifts the focus to what is working well, what is possible, and what is life-giving. This orientation reflects the understanding that meaning is fluid, context-dependent, and co-constructed.

Dialogical Inquiry- Relational constructionism privileges dialogue over diagnosis. AI enacts inquiry as a relational process, inviting reflection, connection, and co-creation. Rather than extracting data, it seeks to humanise understanding through shared exploration.

Valuing Local and Contextual Knowledge- Rather than pursuing universal truths, AI—aligned with relational constructionism—honours situated knowledge and the lived experiences of individuals within systems. This makes AI particularly resonant in complex and diverse settings such as the NHS, where multiple perspectives and narratives coexist.

Ethics of Participation- Relational constructionism emphasises relational ethics—respect, inclusion, and responsiveness. AI embodies these principles by engaging stakeholders (patients, staff, family carers) in shaping the inquiry, envisioning futures, and co-creating change.

In summary, relational constructionism offers a philosophical grounding for AI through the following themes:

- Positioning the inquirer as part of, rather than separate from, the inquiry process.

- Valuing multiple forms of local and contextual knowledge and practice.
- Recognising the influence of historical, political, and cultural knowledge, and its situational use.
- Acknowledging the inquirer's own knowledge and practice as one among many communities of practice.
- Viewing inquiry itself as a form of intervention—one that is co-agreed and co-enacted by participants (Van der Haar & Hosking, 2004).

Person-centred Care

Person-centred care is underpinned by the recognition of the person as an individual who can experience life and relationships, despite the progressive nature of the disease (Edvardsson et al., 2008, Kitwood, 1997a). Its definition encompasses:

> "*supporting the rights, values and beliefs of the individual; involving them and providing unconditional positive regard; entering their world and assuming that there is meaning in all behaviour, even if it is difficult to interpret; maximising each person's potential; and shared decision making" (Edvardsson et al., 2008 p. 363).*

A summary review of the evidence underpinning the concepts and theory of person-centeredness, incorporating an overview of national strategic frameworks that influence the development of person-centred practice in different counties identified significant developments in the theory and practice of person-centres in nursing and healthcare. However, it was identified that there is a need to develop more strategic multi-professional approaches to the development and implementation of person-centred practices (McCormack et al., 2015).

The use of the terms "person-centredness" "and person-centred care" have become increasingly common in health and social care services globally. The term is often synonymous of providing high quality healthcare, yet it is representative of something more significant than that, namely an association that has an explicit focus on humanising health services, ensuring the patient/client is at the centre of care delivery (McCormack et al., 2015).

McCormack et al., 2015 in their summary review of the evidence underpinning the concepts and theory of person centredness discuss significant developments in the theory underpinning person-centredness in nursing and healthcare. However, as evidenced by the accounts of in-country developments, internationally there is a need to develop more strategic multiprofessional approaches to the development/implementation and evaluation of person-centred practices. They suggest that:

- National developments in person-centred healthcare need to reflect the diversity of strategic approaches internationally.
- While a common language of person-centredness is emerging, there is a need for clarity over how this is operationalised in everyday practice situations.

The use of the terms ‘person-centredness’ and ‘person-centred care’ has become increasingly common in health and social care services at a global level. A sceptic might argue that the term is being used as a ‘catch-all’ for everything to do with high-quality health and social care, but McCormack et al., 2015 would contend that it is representative of something more significant than this, namely,” *a movement that has an explicit focus on humanising health services and ensuring the patient/client is at the centre of care delivery”*, pg. 2. In this context, the wealth of evidence supporting the processes and outcomes associated with person centredness in health and social care is constantly growing and becoming progressively diverse.

Furthermore, published evidence to date has discussed the meaning of the terms personhood and person-centredness (Dewing, 2004; Slater, 2006; Edvardsson et al., 2010), offered insights into the cultural and contextual challenges connected to implementing a person-centred approach (McCormack et al., 2008; McCormack and McCance, 2010; McMillan et al., 2010; McCance et al., 2013; Yalden et al., 2013), and examined the emergence of frameworks such as the authentic consciousness framework (McCormack, 2003), the senses framework (Nolan et al., 2004) and the person-centred nursing framework (McCormack and McCance, 2006; 2010) together with the application and testing of these frameworks in practice (Ryan et al., 2008; McCormack et al., 2010a; 2010b; McCance et al., 2010; McCormack et al., 2011).

Laying the foundations of a person-centred culture requires a continuous commitment to practice developments, service improvements and ways of working that embody continuous feedback, reflection and engagement methods that enable all voices to be heard. In the body of evidence, the use of frameworks to inform such work is instrumental. One framework most often cited is that of McCormack and McCance (2010). The framework comprises four constructs:

- Prerequisites focus on the attributes of the nurses and include being professionally competent; having developed interpersonal skills; being committed to the job; being able to demonstrate clarity of beliefs and values; and knowing self.
- The care environment focuses on the context in which care is delivered and includes appropriate skill mix; systems that facilitate shared decision making; effective staff relationships; organisational systems that are supportive; the sharing of power; the potential for innovation and risk taking; and the physical environment.
- Person-centred processes focus on delivering care through a range of activities and include working with patients' beliefs and values; engagement; having sympathetic presence; sharing decision making; and providing holistic care.
- Outcomes, the central component of the framework, are the results of effective person-centred nursing and include satisfaction with care; involvement in care; feeling of wellbeing; and creating a therapeutic environment (McCormack et al., 2015).

Figure 3: Person-Centred Practice Framework (McCormack & McCance 2017)

In UK academia, the development of a person-centred care framework has seen a significant focus on integrating the concept into various healthcare curricula, particularly within nursing and medical programs. Universities actively researching and promoting practices that prioritize patient needs, values, and preferences through teaching methods like dialogic approaches, emphasizing shared decision-making, simulated techniques and incorporating patient perspectives in learning environments; this evolution is largely driven by policy changes within the NHS that increasingly advocate for person-centred care as a core principle of quality healthcare delivery.

In England, there is a movement to mainstream ideas associated with person-centred care. McCormack et al., 2015, suggest this can be quantified within micro, mezzo and macro levels within the healthcare system. For example, at the macro level, the National Institute for Health and Care Excellence (2011) begins its guideline 136 on service user experience in mental health, stating best practice is to promote person-centred care. The National Dementia Strategy (2009) cite 17 key objectives to ensure that there are significant improvements across 3 areas, improved awareness, earlier diagnosis and intervention and a higher quality of care, person centred care is alluded to in objective 6 “which are responsive to the personal needs and preferences of each individual “. NICE Guideline (NG97) (2018), for dementia, refer to Person centred Care across the following areas:

- 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 persons’ perspective.
- The importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

The SIGN 157 guidelines for delirium, (Appendix 3), highlight the importance of person-centred care in point 1.2.1 of their overall objectives, suggesting PCC should be the focus of the guideline.

At the macro level, it is the focus on developing an effective culture, albeit still being centred on organisational culture rather than workplace cultures, that are threaded through policy and local strategy. Specifically, staff wellbeing and engagement between managers and staff appear most influential (Maben et al., 2012). For example, the NHS annual staff survey measures staff engagement, an attribute of culture necessary for effective care. Although results are improving slowly, in comparison over 10 years, in 2013 in response to the survey statement ‘the care of patients/service users is my organisation’s top priority,’ two-thirds (66%) of staff agreed, this has since increased to 75.4% in 2023, suggesting 25% are saying it is not the top priority. Only 57.7% would recommend their organisation as a place to work, in 2023 this increased to 61.12%, suggesting that person-centred cultures and/or working environments conducive to its delivery are not an established reality.

There appears to be a gap between the ideals of policy and practice as experienced by staff and service users, staff often frustrated that organisational constraints one of many barriers to delivery PCC get in the way. In addition, the intentions of education/learning strategies and programmes of delivery appear to be misaligned (McCormack et al., 2015). A systematic review of the evidence of effectiveness of educational interventions in promoting person-centred care in dementia services concluded that there was very little evidence that education programmes can reliably produce substantial improvements in working practices, suggesting education must be supplemented by other learning methods, such as working alongside good role models and organisational support to motivate staff and provide opportunities to deliver PCC (Carparelli et al., 2024).

The ability to manage and read emotions is an important skill for any healthcare professional and might potentially enhance person centred care. This in turn would help improve the quality of professional patient relationships and increase patient levels of satisfaction with care and improve carer outcomes and experiences.

A report from a national nursing education summit in 2013, co-led by the Canadian Association of Schools of Nursing and the Canadian Nurses Association, highlighted the need for development of emotional intelligence.

‘Enable learners to develop emotional intelligence and self-awareness, an understanding of cultural, social and organizational contexts, an orientation toward safe, person-centred care, and the ability to create partnerships with patients and families to achieve optimal outcomes’ (Canadian Association of Schools of Nursing, 2014, pg. 5).

Principles of relationship centred care

An alternative way of understanding good care provision is one that focuses on the interactions and who is involved. Relationships provide the context for many essential functions and activities in healthcare. Within relationships, we exchange information, allocate resources, arrive at diagnoses, choose treatments, and assess the outcomes of care. None of these are carried out uniquely by one individual, all are mediated by the qualities of the various relationships that link patient, clinician, team, organisations, and community. Relationship-centred care (RCC) is built upon 4 related principles that are described below:

- Principle 1. Relationships in healthcare ought to include dimensions of personhood as well as roles.
- Principle 2. Affect and emotion are important components of relationships in healthcare.
- Principle 3. All healthcare relationships occur in the context of reciprocal influence.
- Principle 4. Relationship centred care has a moral foundation.

Despite a wealth of literature exploring human interaction, the emergence of person-centred care educational programmes and advocacy for relationship approaches, challenges remain around how communication between the older person, their family carer and staff that helps to promote policy and practice aspirations is realised (Lown & Manning, 2010, Dewar & Nolan 2013, Dewar et al., 2011, Sheard 2007).

Doane (2002) suggested that dignified and compassionate care can be taught, but traditional models of delivering education focusing on behavioural communication skills listening and questioning, do not adequately address the relationship element that is fundamental to delivering compassionate care.

A 20-year scoping review of RCC, Soklaridis, (2016) identified 69 publications mainly from the United States and the United Kingdom from authors from various academic disciplines, of which medicine and nursing were dominant. Thematic analysis revealed the most dominant definition of RCC from the literature was that of the Pewter Fetzner report and focused on the central role of relationships between practitioners, their patients, the community and other practitioners in providing quality care and improving outcomes. The concept of RCC was found to be influenced by theories of sociology, social psychology and psychiatry, Table 1 provides a summary.

Table 1: Theoretical approaches in RCC literature (adapted from Soklaridis et al., 2016)

Theoretical Approach	Definition	Authors
Sociology		
Social Construction	Social construction refers to the way we present ourselves to other people and how that is shaped by our interactions with others, our life experiences and beliefs, and how we believe others perceive us.	Adams and Gardiner, 2005 Cooper et al., 2006 Buckley, 1967 Buckley, 1968
Complexity Theory	Complexity theory seeks to understand how order emerges in non-linear systems, such as social systems and biospheres. The systems continuously seek to balance the tension between focus for innovation with the competing need for stability and structure.	Safran et al., 2006 Suchman et al., 2011 Sucham et al., 2006 Haken H. In Yates et al., 1987
Organisational Theory	Organisations are described as social systems attempting to “survive” in their environment. Studies by anthropologists and sociologists revealed patterns of cooperation, shared norms, and	Dix et al., 2008 Gaboury et al., 2011 Nolan et al., 2001 Walker et al., 1987 Walker et al., 1998

	conflicts between and among managers and workers.	
Social Psychology		
Appreciative Inquiry	Appreciative inquiry focuses on the “best” in people, their organisations, and their social system.	Dewar and Nolan, 2013 Suchman et al., 2011
Self Determination Theory	Psychologists Edward Decci and Richard Ryan developed a theory of motivation positing that people are driven by a need to grow and gain fulfilment. The self-determination theory posits that individuals are actively directed toward growth and through gaining mastery over challenges develop a deep and cohesive sense of self.	Beach and Inui, 2006 Bolles and Maley, 2004 Cooper et al., 2006 Madigan, 2001 Tresolini CP; Pew-Fetzer, 1994
Psychiatry		
Self-relationship	The self-relationship approach looks within the unconscious to enter dialogue with one’s deepest self. It is an approach to therapy and	Knight et al., 2001

	personal change that reconnects mind-body processes.	
Narrative Therapy	Narrative theorists draw on fields on rhetoric, philosophy, cognitive science, and gender theory to explore how narratives work as both texts and strategies for navigating experience.	Dewar and Nolan, 2013 Ensher and Clark, 2011 Nolan et al., 2006 Thomasma, 1996

Employing a Relationship-Centred Approach

It is suggested that dementia is as much a relational disability as it is a physical or neurological one (Grosvenor et al., 2021; Shakespeare et al., 2019). People living with dementia (PLWD) can maintain reciprocal relationships, even at advanced stages of the illness (Hughes, 2014; Killick, 2013; Sabat et al., 2008). Social networks, relationships and the levels of support an individual with dementia receives will influence their experience and inclusion within society. A relational model of disability offers an approach to dementia that is enabling in how it addresses deficits, treatments and actions to remove social, attitudinal and architectural barriers (Shakespeare et al., 2019).

Service delivery for people living with dementia is not without its challenges. These challenges can be experienced as a result of an individual's limited capacity to engage socially, acting in a way that may cause concern or distress to those around them (James & Jackman, 2017; Zimmerman et al., 2014). Kitwood's understanding of personhood and empowerment fostered the development of a person-centred service model that prioritised the relational capacity and interdependence within a dementia support outreach programme in Sheffield, UK. A key finding of this study was the importance of the triadic relationship formed between healthcare professionals, family carers and the person with dementia (Stewart et al., 2022). Although this work was originally focused on older people rather than specifically PLWD, Nolan (2001) developed the impact of relationship centred dementia care services through the “senses framework”. This framework captured the subtleties of caring relationships and represent the intra and interpersonal aspects of giving and receiving care.

Central to good dementia care are positive relationships between staff, the PLWD and their family carer (Nolan, 2006, Nolan & Allan, 2012 and Nolan et al., 2004) advocate relationship centred care which moves the focus from just being on the person receiving care to creating an enriched environment which supports relationship and where the needs of the family and staff are considered. Nolan et al., (2006) developed and empirically tested the senses framework; advocating that the person receiving care, family carers and carers that are paid should all experience relationships that promote the six Senses (Figure 4, Table 2). The ‘Framework’ suggests that good care is achieved through relationships that promote a sense of:

- Security - feeling safe within relationships
- Belonging - feeling included
- Continuity - noticing links and consistency
- Purpose - having personally valuable goals
- Achievement - having a sense of progress towards a goal
- Significance - feeling that you matter

Figure 4: The Senses Framework. Nolan et al., 2006

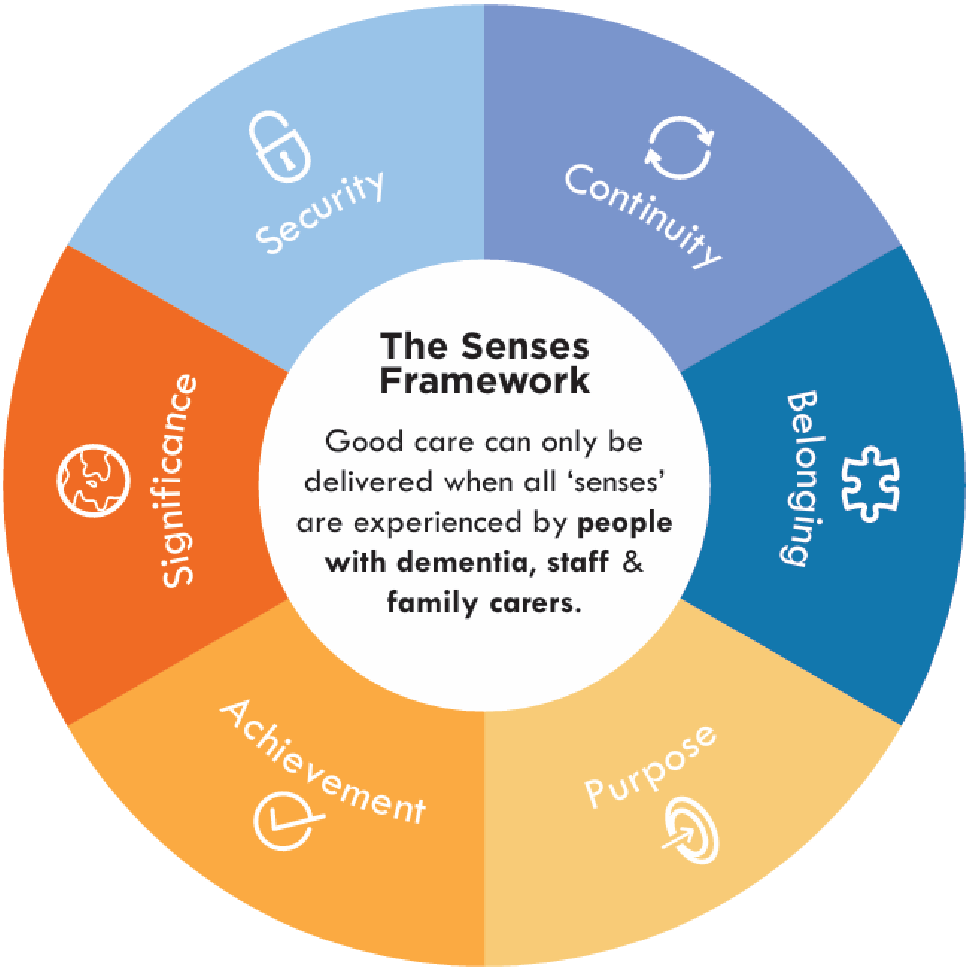


Table 2: Senses Framework

Sense of Security - To feel safe
For older people: Attention to essential physiological and psychological needs, to feel safe and free from threat, harm, pain and discomfort.
For staff: To feel free from physical threat, rebuke or censure. To have secure conditions of employment. To have the emotional demand of work recognised and to work within a supportive culture.
Sense of Belonging
For older people: Opportunities to form meaningful relationships, to feel part of a community or group as desired.
For staff: To feel part of a team with a recognised contribution, to belong to a peer group, a community of gerontological practitioners.
Sense of continuity - To experience links and connections
For older people: Recognition and value of personal biography. Skilful use of knowledge of the past to help contextualise present and future.
For staff: Positive experience of work with older people from an early stage of career, exposure to positive role models and good environments of care.
Sense of purpose - To have a personally valuable goal(s) to aspire to
For older people: Opportunities to engage in purposeful activity, the constructive passage of time, to be able to pursue goals and challenging pursuits.
For staff: To have a sense of therapeutic direction, a clear set of goals to aspire to.
Sense of achievement - To make progress towards these goals
For older people: Opportunities to meet meaningful and valued goals, to feel satisfied with one’s efforts.
For staff: To be able to provide good care, to feel satisfied with one’s efforts.
Sense of significance - To feel that “you” matter as a person
For older people: To feel recognized and valued as a person of worth, that one’s actions and existence are of importance, that you ‘matter’.
For staff: To feel that gerontological practice is valued and important, that your work and efforts ‘matter’.
For family carers: To feel that one’s caring efforts are valued and appreciated, to experience an enhanced sense of self.

Relationship-centred practice is instrumental to delivering high quality dementia care. Dewar, (2017) pg. 1375 suggests that “evidence is strong about the centrality of human interaction in developing relationships that promote dignity and compassion”.

A key contribution to healthcare practice is The Caring Conversations Framework, rooted in the principles of appreciative inquiry, was developed by Belinda Dewar, adopted for use in a variety of settings including hospitals, community care and residential care.

This framework aims to foster compassionate and relational interactions in healthcare settings. It emphasises seven attributes: **be courageous, celebrate, connect emotionally, be curious, consider other perspectives, collaborate, and compromise**. These attributes guide practitioners in creating meaningful and supportive relationships with patients, families and colleagues.

The framework has delivered positive outcomes such as improved self-awareness, stronger relationships and more open dialogue. Dewar's work has been instrumental in promoting dignity, compassion and person-centred care.

Despite a wealth of literature exploring human interaction, the emergence of person-centred care educational programmes and advocacy for relationship approaches challenges remain around how communication between the older person, their family carer and staff that helps to promote policy and practice aspirations is realised (Lown & Manning, 2010, Dewar & Nolan 2013, Dewar et al. 2011, Sheard 2007).

In summary, Dementia care has been conceptualised by various frameworks and models over time as based on Person Centred Care, Dementia Care Mapping and Behavioural and Psychological needs management reflecting a commitment to individuals' needs to be valued and seen as people who are more than their diagnosis or their deficits.

Data collection and COVID-19

The COVID-19 pandemic significantly impacted the planning and delivery of the study. According to the Office for National Statistics (ONS), 17% (11,623) of registered deaths due to COVID-19 involved dementia as a pre-existing condition (ONS, 2021). During the period from May 2020 to March 2021, I was redeployed to establish and manage a ward dedicated to end-of-life care for patients with COVID-19. This experience was emotionally demanding and required considerable resilience.

As a result, non-participant data collection was temporarily suspended and only resumed in August 2022. Even at that time, intermittent COVID-19 outbreaks continued to affect the data collection site, disrupting care delivery and limiting family access to patients. For instance, if a single patient in a bay of 4–6 tested positive, all patients in that bay were treated as exposed and cohorted accordingly. This led to strict visitor policies, often limiting family carers to one-hour visits with only one visitor permitted. In some wards, such restrictions became routine practice, inadvertently contributing to patient isolation.

Although data collection occurred after the lifting of international lockdowns, participants frequently described the enduring effects of social distancing and the closure of public spaces on individuals living with dementia.

Thesis Structure

Chapter 2 is a scoping review of the literature. The review sets out the review methods, summarises and critiques the existing evidence on what supportive interventions are known that provide care for patients with DSD that involve family carers in hospital and will include:

- An exploration of how family and HCP provide care together for patients with DSD.
- A summary of the evidence of the impact of these interventions.
- Suggestions for further service development and research.

Chapter 3 discusses the research world views that framed this thesis and introduce the reader to the research method and relational process of appreciative inquiry research. I provide a rationale for this approach.

Chapter 4 presents the findings from the non-participant observation during the Discovery stage of the study.

Chapter 5 presents the interview findings from the Discover, Dream and Design phase.

Chapter 6 presents the discussion, conclusion and recommendations arising from the findings. Their significance for policy, practice, education and research is also addressed.

Chapter 7 provides a reflection on the study design and my role as a practitioner/researcher.

Chapter Summary

This chapter has provided the contextual background, theoretical underpinning and motivation for this study. The two phases of the thesis have been outlined along with the aims and objectives how delirium superimposed on dementia is defined and the relevance of relational working or as it is more traditionally understood, person-centred care as recognised frameworks of practice.

Chapter 2 - Scoping Review

Introduction

This chapter presents Phase 1 of the study; a scoping review (Caroline Ashton-Gough et al, 2025) designed to identify, appraise and analyse existing cross-discipline primary research exploring supportive interventions involving family carers and staff providing care for patients with DSD in an acute hospital setting. The review approach and methods are explained within this chapter. The findings are presented and used to inform the focus, design and conduct of Phase 2 of the study, an Appreciative Inquiry (AI) intervention study.

The review sought to identify and investigate the constructs, approaches and intervention types of approaches to care for patients with DSD in hospital. The review findings provided a systematic approach of the current evidence in relation to what interventions involving family carers are known, and what is the evidence they are working in relation to the current understanding of caring for patients with DSD in hospital (Ashton-Gough et al., 2025).

The review was conducted utilising the methods outlined in the Cochrane Handbook of Systematic reviews of Interventions (Higgins and Green, 2008a). The review protocol (Ashton-Gough et al.) was developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and checklist (Moher et al., 2009). To limit review duplication and promote transparency and replicability, the protocol was registered with PROSPERO (registration number CRD) (Appendix 5).

Methods

Aim

The aim of this review was to review the evidence on supportive interventions involving family carers on the health outcomes of patients with delirium superimposed on dementia in in-patient hospital settings, to apply transferable learning to people living with dementia with delirium superimposed in hospital.

Review Objectives

- Explore what kind of organisational, educational and peer support can deliver an improved nurse- family carer relationship for delirium prevention for hospital patients with dementia.
- Explore the evidence that approaches that involve patients with Delirium Superimposed on Dementia (DSD), nurses and their relatives/supporters lead to improved outcomes for the patient and experience for the carer.
- Explore how DSD is understood and/or characterised for people living with dementia and their (staff and family) carers.
- Explore what interventions in acute hospitals that support patients with DSD, and their family involve volunteers.
- Seek to understand the barriers and facilitators to effective relationship centred care when providing supportive interventions for patients with DSD.
- Identify implications for providing relationship centred care for patients with DSD in dementia care practice in hospital, policy and future research.

Inclusion Criteria

Inclusion criteria are presented in Table 3 below. A 10-year time limit from 2009-2019 was applied to reflect emerging research in the field of delirium care. The focus of the review was specific to patients that were known to have a diagnosis of dementia with suspected or confirmed delirium superimposed. Due to the nature of the complexity of recognizing DSD, it was decided that studies that reported patients as having a cognitive impairment alone without reporting of patients with a dementia diagnosis were excluded to concentrate on the people with a known diagnosis. The number of patients with dementia who experience delirium in hospital is an under researched but an emerging area of care.

All studies reporting on all intervention and observational designs that focused on family, or their proxies (e.g. unpaid volunteers) being involved in the care of patients with DSD. Inclusion criteria were studies involving:

- Hospital in-patients with dementia (all types and stages) or cognitive impairment.
- Inpatients with delirium superimposed on dementia/cognitive impairment.
- Patients with dementia identified as at risk of developing delirium.
- Unpaid volunteers who could represent the needs of the patient.
- Nurses caring for people with dementia and delirium.
- The multidisciplinary team working with patients with dementia and superimposed delirium.

Notably, evidence identified there was research that involved volunteers to act as the patient's advocate. As there was limited research focusing on family carers it was decided to include volunteers because of their status on the ward as speaking for the patient.

Exclusion Criteria

Studies not reporting patients with dementia were excluded. Studies were excluded if conducted with older people with dementia and delirium in a long term or community setting. Studies were also excluded if we could not distinguish between information about family or family proxy activities from that of the healthcare professionals.

Table 3: Inclusion Criteria (Ashton-Gough et al., 2024)

Publication Language	English
Publication Dates	2009-2019, revisited in 2023
Target Population	Adults over the age of 18 years, with a confirmed diagnosis of dementia or with cognitive impairment/suspected dementia
Study Setting	Hospital
Study Types	All quantitative and qualitative research designs
Intervention Types	Any intervention designed to provide support for patents with delirium superimposed on dementia that included working with family carers
Primary Outcomes	Any supportive intervention involving the care of patients with DSD and their family carer that had a positive effect, improved patient/carer experience and staff satisfaction
Additional Outcomes	Family Carer and/or health or care professional satisfaction, and any documented adverse effects (e.g. falls, increased distress, length of stay, mortality

Search strategy

An initial search was conducted in 2019, and re-run in 2023, yielding 2 additional papers for inclusion (see figure 5). The search strategy was applied to cross-disciplinary databases associated with cognitive impairment and dementia care. Electronic databases searched, an example of the full search query for CINAHL is shown in Table 4.

Figure 5: Prisma

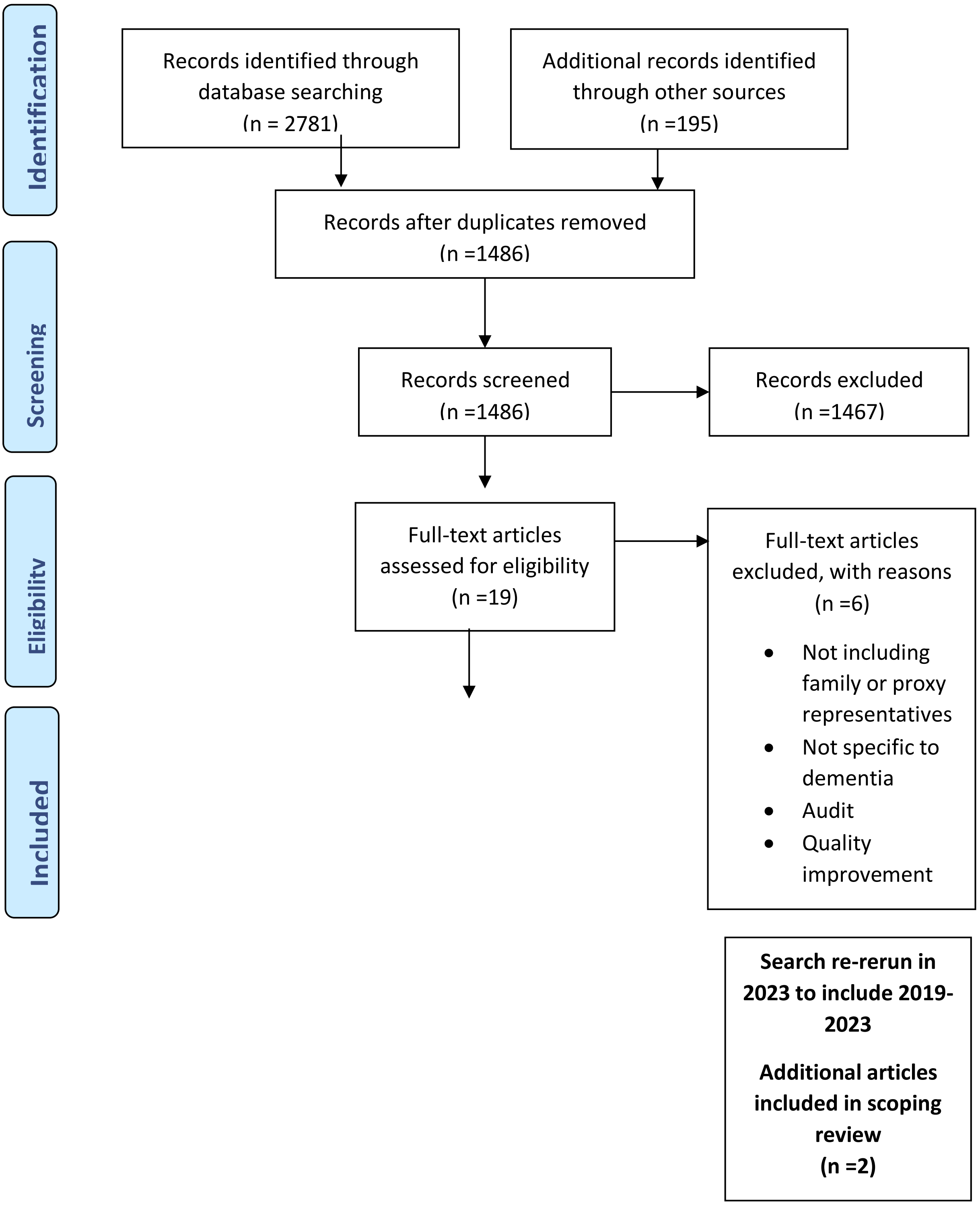


Table 4: Example of the building blocks used in one database search

Building blocks in the CINAHL search				
OR	**AND**			
	• exp "COGNITION DISORDERS"[MH] • exp "DEMENTIA"[MH] • cognitive ADJ3 impairment • cognitive impairment* • cognitive disorder* • cognitive ADJ3 disorder* • dementia	• "exp DELIRIUM"[MH] • Delirium	• exp "HOSPITALS, DISTRICT" • exp "HEALTH FACILITY ENVIRONMENT" • hospital* • ward* **NOT** • exp "COMMUNITY HEALTH SERVICES" • community*	• exp "NURSING"[MH] • nurse*

Medical Subject Heading (MeSH) search terms were combined with Boolean operators AND, OR for an inclusive search strategy for PubMed and other electronic databases which recognises Mesh terms. Alternative but equivalent free text terms operated with “wildcards” and truncations were adapted to search other databases as appropriate. MeSH terms and their subheadings were applied to full text. Free text search terms were limited to title and abstract only, to promote relevance of results.

Forward and backward citation searches were undertaken on Google Scholar to detect any additional relevant studies. Searches were undertaken in June 2019, updated in July 2023 prior to publication, and revisited in October 2023. Alerts were created using the search terms on Google Scholar, Psycho Info and British Library to provide a constant awareness of relevant contemporary literature. Support from the local clinical librarians at the study site highlighted relevant studies as well.

Amendments

To promote transparency and replicability and to reduce bias, a regular revisit to PROSPERO ensured individuality, (https://www.crd.york.ac.uk/prospero/) registration number CRD 42019130369 and in the published review (Ashton-Gough et al, 2024), but no amendments to the original application were required. The search was conducted using the databases listed in Table 5.

Table 5: Search results by database

Database		Number of papers	
Cinahl Complete	EBSCO	92	23.02.2023
MEDLINE	OVID	116	20.02.2023
Embase	OVID	336	20.02.2023
PSCYH INFO	Proquest	33	23.02.2023
Cochrane Library	Cochrane	110	23.02.2023

Study Screening and Data Extraction

Studies were downloaded into a word document. Duplicates were identified and excluded. The titles and abstracts of citations were reviewed independently by three reviewers (CAG, CG and JL) to decide whether papers were retrieved in full before being appraised independently by two reviewers (CAG and CG) for eligibility. Reference lists of included studies were reviewed to identify any relevant papers not captured through electronic searches. Excluded studies included: studies not involving or reporting on family carer involvement, (Cheong, 2016, Ervin and Moore, 2014, Ruff et al., 2018), or reportable family carer outcomes (Hasemann et al., 2016, Stenvall et al., 2012), reporting on experience and emotional distress only (Lim, 2022, Morandi et al., 2015), not specific to delirium, (Porock et al., 2015, Parke, 2019).

Full text manuscripts of all potentially relevant citations were obtained and screened. Data was extracted using the format of the review objectives with the aim to include information about the study design, participants and outcomes. The process for filtering the results can be seen in Figure 5 PRISMA diagram (Moher et al., 2015).

Quality Appraisal

Articles that met the inclusion criteria were assessed using the JBI standardised critical appraisal checklists (Lockwood et al., 2015; Tufanaru et al., 2020).

Two reviewers reviewed the papers. Where consensus was not reached, a third reviewer was involved to resolve the decision. However, it is recognised that the framework's efficacy depends on the researcher's interpretation of the results.

Quality Assessment

Studies were downloaded into a word document. Duplicates were identified and excluded. The titles and abstracts of citations were reviewed independently by three reviewers (CAG, CG and JL) to decide whether papers were retrieved in full before being appraised independently by two reviewers (CAG and CG) for eligibility. Reference lists of included studies were reviewed to identify any relevant papers not captured through electronic searches.

Analysis

Owing to heterogeneity, and low numbers of quantitative studies meta-analysis was not achievable. Results of qualitative and quantitative studies are therefore reported in narrative format.

Qualitative studies were synthesised using thematic analysis. The review objectives and topics in primary studies were used to map the range of data and identify recurrent themes. The method of synthesising qualitative research enabled in depth exploration of themes and areas of interest (Braun and Clarke, 2006, Clarke and Braun, 2014).

Results

After screening, 19 articles met the inclusion criteria after the search was updated in September 2023 (Ayton et al., 2020, Bateman et al., 2016, Blair et al., 2018, Boltz et al., 2015, Collier et al., 2020, Fick et al., 2011, Goldberg et al., 2013, Kang et al., 2016, Martinez et al., 2012, Mailhot et al., 2020, Paulson et al., 2016, Teodorczuk, 2014, Wazynski 2018, Wong-Shee et al., 2014, Yevchak et al., 2017) and were reviewed for quality and eligibility, and 6 were excluded after quality appraisal for not including family or proxy representatives (e.g., volunteers); not being specific to patients with dementia; being an audit or quality improvement project.

The original search completed in 2020 was re-run in 2023, yielding two additional papers for inclusion. See Figure 5.

Study Quality

The Study quality of the papers ranged from 70-90%, (Table 6 and 7, Appendix 5 and 7).

Table 6: Study Quality-Qualitative Studies

Citation	Study design	JBI critical appraisal questions													Overall
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	
Ayton et al (2019)	Mixed Method	Y	Y	Y	Y	Y	N	N	Y	Y	Y	N/A	N/A	N/A	Include
Bateman et al (2016)	Quasi-Experimental	Y	Y	Y	N	N	Y	Y	Y	Y	U	N/A	N/A	N/A	Include
Blair et al (2018)	Mixed Methods	Y	Y	Y	N	N	Y	Y	Y	Y	Y	N/A	N/A	N/A	Include
Boltz et al (2015)	Comparative Repeated Measures study	Y	Y	Y	N	N	N	N	U	Y	Y	N/A	N/A	N/A	Include
Collier et al (2020)	Qualitative	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N/A	N/A	N/A	Include
Fick et al (2011)	Prospective Cohort	Y	Y	Y	N	N	Y	N	Y	U	Y	N/A	N/A	N/A	Include
Kang et al (2017)	Mixed Methods	N	Y	Y	Y	N	N	U	U	Y	Y	N/A	N/A	N/A	Include
Mailhot et al, (2020)	Validation	Y	Y	Y	Y	U	N	N	Y	U	Y	N/A	N/A	N/A	Include
Paulson et al (2016)	Qualitative	Y	Y	U	U	Y	N	N	Y	Y	Y	N/A	N/A	N/A	Include

Teodorczuk et al (2014)	Grounded Theory	Y	Y	Y	Y	Y	N	N	N	Y	Y	N/A	N/A	N/A	Include
Wong Shee et al (2014)	Qualitative	Y	Y	Y	U	U	N	N	Y	N	Y	N/A	N/A	N/A	Include
Yevchak et al (2017)	Exploratory Descriptive	Y	Y	Y	U	Y	N	N	U	Y	Y	N/A	N/A	N/A	Include

Key: Y = yes; N = no; U = unclear; N/A = not applicable

Table 7: Study Quality: Randomised Control Trial

Citation	Study design	JBI critical appraisal questions													Overall
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	
Goldberg et al (2013)	RCT	N	Y	Y	Y	N	U	N	Y	Y	Y	Y	Y	Y	Include
Martinez et al (2012)	RCT	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	N	Y	Include
Waszynski et al (2018)	RCT	Y	Y	Y	N/A	Y	Y	Y	N	Y	Y	Y	Y	Y	Include

Key: Y = yes; N = no; U = unclear; N/A = not applicable

A high risk of bias was noted in some studies. For example, one study, Mailhot et al., 2020 discuss a diagnostic bias which may have skewed estimated sensitivity and specificity. Wasynski et al., 2018 spoke of measures to address bias having an expert in the field to assess distressed behaviours, and Goldberg et al, discuss compromises in trial design which may have introduced bias. Five studies did not provide a clear ethics statement, Boltz et al., 2015, Fick et al., 2011, Mailhot et al., 2020, Paulson et al., 2016 and Yevchak et al., 2017.

All the qualitative studies achieved a maximum score in at least seven of the thirteen areas assessed. Two papers did not clearly articulate sampling strategies. One study reported a bias suggesting the design violated best practice for a RCT, by recruiting participants after randomisation (Goldberg et al., 2013), low patient sample size was reported in studies, N=24 (Boltz et al., 2015, N=30 Wong Shee et al., 2014, N=15 (Fick et al., 2011 with a staff sample of N-6, N=12 (Kang et al., 2016). Lack of evaluation of family care givers was reported in (Boltz et al., 2015), with a low family carer sample, N=5 (Collier et al., 2019), N=3, (Wong-Shee, 2014), N=6 (Kang et al., 2017), N=13 (Fick et al., 2011) and a low incidence of dementia reported N=21, 6% of the included patients (Martinez et al., 2020). Finally, a diagnostic bias was reported (Martinez et al., 2020), recognising while the Cam is a validated delirium screening tool, this has not been specifically validated for use in the ED.

Characteristics of included studies and Participants

All included studies were published between 2011 and 2020, with the majority (n=9) of studies being published in the last 10 years. This suggests an increased awareness of non-pharmacological approaches to delirium care for people with dementia in line with recommendations from recent policies/guidelines, for example SIGN 157, NICE delirium guidelines (NICE 2023).

Of the fifteen studies, six studies were conducted in the United States of America (USA), five in Australia, two in the United Kingdom (UK), one in Chile and one in South Korea. Settings varied from rural to metropolitan hospitals, with most studies conducted in older people’s wards including rehabilitation, geriatric, specialist medical/mental health, and surgical wards. Three studies were Randomised Controlled Trials (Goldberg et al., 2013, Martinez et al., 2012, Waszynski, 2018). The remaining studies included qualitative methods (Collier et al., 2020, Mailhot et al., 2020, Paulson et al., 2016, Teodorczuk et al., 2014, Wong Shee et al., 2014, Yevchak et al., 2017), mixed methods (Ayton et al., 2020, Blair et al., 2018, Kang et al., 2017), prospective cohort (Fick, 2011), quasi-experimental (Bateman et al., 2016), and comparative (Boltz et al., 2015).

Duration of data collection varied and was often reported as a period of observation. Ward based observations ranged from two days to eighteen months. The characteristics of the 15 studies included in this review are outlined in Table 8.

Table 8: Study Characteristics

Author, year and location	Study design and setting	Number of participants, age and condition	Type of family carer Intervention	Comparison/ Control and Duration of data collection	How Dementia and delirium was assessed	Outcomes measured
Ayton et al., 2020 Australia	Mixed methods. Acute and sub-acute metropolitan hospital (Pre implementation study)	Nurses (N=73) (returning surveys) patient/ caregiver dyad interviews (N=4) Key stakeholder interviews (Consultant, OT, Volunteer coordinator etc.) (N=7) Condition- Dementia/ Delirium	1:1 companionship for patients with dementia and/or delirium provided by volunteers	Not reported	Not reported	Acceptability of the programme for key stakeholders—patients, caregivers, nurses, hospital staff and volunteers.
Bateman et al., (2016) Australia	Quasi-experimental; pre-post design. Acute rural hospital	Patients Aged> 65 years |(or> 50 years for Aboriginal persons) (N= 64) Dementia/ delirium Diagnosis, known risk factors for	Volunteer training programme; including completion of personal profile with the patient or family carer	Data collected at baseline and at 8 months	A diagnosis of dementia OR A Diagnosis of Delirium OR Mini Mental State Examination (SMMSE) score of<25/30 OR one or more risk or precipitating factors for delirium	Patient Outcomes: Use of Antipsychotics/ Psychotropic Medications. Use of analgesia Use of antidepressants Length of stay,

		Delirium or SMMSE< 25/30				Number of falls Incidence of delirium Staff/Volunteer Outcomes Staff: Attitude to PCC Volunteers: knowledge and confidence. Attitude to PCC.
Blair et al., (2018) Australia	Non-randomised controlled trial. Seven acute rural Hospitals located in Southern New South Wales local health district (SNSWLHD).	Patients (N=270). Family members (N=80). staff (survey) (N=119). Staff (focus groups) (N=46); volunteers (N=44). Patients had dementia or delirium Condition-Dementia and/or delirium	Volunteer training programme. Completed a Personal Profile with the family carer Family interviews/ surveys Focus groups	Control group of historical patients admitted 12 months prior to programme. Beginning of Project (data recorded over 8 months)	Not reported	Increased safety, and quality of care. Increased patient well-being. Reduction in family care burden. Reduction in nursing care burden.
Boltz et al., 2015 USA	Comparative repeated measures study. Five medical units in two hospitals in Northeast USA.	Patients (Older adults aged 65 or over). English speaking/ reading; a positive mini cog; Intervention group N=44; Non-intervention group n=42.	A function focused model of care intervention including 4 components, (1) environmental and policy assessment, (2) staff education, (3) individualised goals, (4) motivation of nursing staff/patients.	One intervention unit in each hospital, three control units Over 18 months	A positive mini-cog assessment	Patient outcomes: ADL performance; walking performance; gait and balance; delirium severity; hospital discharge outcomes. Family caregiver measures: preparedness for caregiving;

		Family caregiver N=86 Dyads.				anxiety and depression; strain; mutuality between caregiver and care receiver
Collier et al., 2020 Australia	Qualitative, using video reflexive ethnography. Specialist older people and evaluation management unit in a sub-acute hospital.	Patients (n = 3); family members (n = 5); managerial staff members (n = 2); clinical staff members (n = 35); and nonclinical staff members (n = 5). Age-not reported Condition-dementia and delirium	Observation of patients, family and staff members.	21 months	Not reported	Team commitment to high quality fundamentals of care. Teamwork. Dementia-friendly environment. Aptitude to working with people with dementia.
Fick et al., 2011, USA	Prospective cohort pilot study testing feasibility of one component of multicomponent intervention. One adult medical surgical unit in an acute care hospital	Patients n=15 Patients /Family N=3 Aged over 65, mean age 83. Dementia diagnosis	Computerised decision support screen (for delirium assessment and management) component of multicomponent intervention for early nurse detection of delirium superimposed on dementia. Study followed consecutively admitted patients and their caregivers for duration of admission.	Study carried out over 14-week period Patients and family carers followed for duration of hospital stay	Aged 65 and over, met criteria for dementia using MBDRS screen. Family caregiver was interviewed using two instruments Modified Blessed Dementia Rating scale and Clinical Dementia Rating Scale. Daily assessment of delirium using a structured	Nurse adherence to and usability of electronic medical record documentation. Narrative feedback on screens. Patient and family satisfaction surveys post discharge.

					interview consisting of MMSE, Observation, and the Confusion Assessment Method (CAM).	
Goldberg et al., 2013 England	Randomised controlled trial. Large acute general hospital in the UK Medical/Mental health unit (28beds)	N=600 patients (310 from specialist unit, 290 from standard care) n=250 sets patient notes Age over 65yr. Patients with dementia and/or delirium	Family carers were recruited, if available and willing to act as an informant. Proactive and inclusive approach to family carers	Randomised to either usual care ward or specialist medical and mental health unit. Recruitment over 18 months Follow up completed at month 21.	Not recorded. Patients included identified as 'confused' on admission (mitigating overlap in delirium and dementia) but not requiring other specialist care.	Number of days spent at home (or in the same care home) in the 90 days after randomisation. Quality of life. Behavioural and psychological symptoms. Physical disability. Cognitive impairment (MMSE). Inpatient falls. Mortality. Patient experience. Length of stay. Carer strain. Carer wellbeing. Carers' satisfaction.
Kang et al., 2016 South Korea	Mixed methods sequential explanatory, pre-post design. One regional general hospital	RNs N=40 recruited for education programme. Purposive sample of RNs N=12 Family Caregivers N=6 No patients recruited.	Individual interviews. Delirium brochures given to family caregivers as part of nurse education programme	Conducted between July 2013 and March 2014. RNs completed surveys at baseline and 3 months after the educational programme Qualitative interviews, 2 months after	Not reported	Impact of education programme. Nurses' knowledge of cognitive impairment. Attitudes to older adults. Nurse initiated efforts to involve family caregivers.

				the programme		
Martinez et al., 2012 Chile	Single-blind randomised controlled trial. Internal medicine ward	Patients N=287 Age->70 years Condition-previous history of cognitive impairment	Non-pharmacological intervention delivered to and by family members, including education on delirium; avoidance of sensory deprivation; presence of familiar objects; provision of clock and calendar in the room; reorientation of patient by family; extended visitation times.	Standard care (N=143). Allocated to multicomponent intervention (N=144). Patients recruited over 8 months with follow-up until last hospital discharge.	All patients at risk of delirium on basis of 1 risk factor <24 on mini-mental state examination	Presence of delirium assessed by CAM. Incidence of falls during hospital stay and complications derived from them.
Mailhot et al., 2020 USA	Validation study. Urban academic emergency department (ED).	Dyads of ED patients aged 70 and older and their family caregivers (N=108 dyads). Condition-with/without dementia	Family caregiver self-administered the family confusion assessment method (FAM-CAM) independently.	For concurrent validity, performance of the FAM-CAM was compared to the reference-standard confusion assessment method (CAM). For predictive validity, clinical outcomes over 6-months were compared by FAM-CAM status (positive /negative)	The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) used for caregiver assessment of the patient’s level of cognitive functioning.	Performance characteristics of the FAM-CAM method. Clinical outcomes 6 months post enrolment by FAM-CAM status: ED visits, hospitalization and mortality.

Paulson et al., 2016 USA	Education initiative implementation within large multisite intervention study. 24 bedded inpatient medicine and acute care of the elderly unit (ACE) at a large medical centre	Nurses (N=32) and ancillary staff (N=14) given brochure. Nurses (N=7) completed feedback survey. No patients recruited	Delirium education brochure for family caregivers. Shared with nurses to be used with family caregivers	implemented over 16 months	Patient data not included	Nurse feedback on use and usefulness of a delirium education brochure for family carers and staff.
Teodorczuk et al., 2014 UK	Implementation and evaluation study. One regional hospital Trust.	Health care professionals (N=48) representing 12 different professional groups. No patients recruited.	Training programme underpinned by learning from patients and family carers	2-day interprofessional dementia and delirium education programme. Course implemented 3 times over 18-month period	Patient data not recorded	Participants' confidence in certain acts of professionalism related to care of confused elderly patients. Changes in attitudes and knowledge.
Waszynski et al., 2018 USA	Single site randomised controlled trial. Mixed factorial design. Acute care, level 1 trauma centre in an inner-city state	Hospitalised patients with dementia experiencing delirium (N=126) Family members (N=56) participated in the production of family video messages.	Family members recruited to produce video message	Family video intervention compared to nature video intervention and usual care. Intervention x 4 time points, Conducted over 9 months.	Hyperactive or mixed delirium evidenced by positive score on CAM, and a score of >0 Richmond Agitation Sedation Scale (RASS), Dementia assessment not recorded.	Medication administration for decreasing agitation. Participant agitation (ABS score).
Wong Shee et al., 2014 Australia	Qualitative design. 30 bed Inpatient rehabilitation unit, large regional health service	Patients (N= 30) Carers (N= 3) Volunteers (N=10) Staff (N=6)	Volunteer diversional therapy programme	Study conducted over 6 months.	Cognitive impairment, defined as a Mini Mental State Examination (MMSE) score <25 25 or a diagnosis of dementia, and had exhibited behavioural disturbance	Staff, volunteers and patients/ carers perceptions (acceptability and feasibility) of intervention.

					(e.g. agitation or wandering)	
Yevchak et al., 2017 USA	Qualitative, exploratory, descriptive study within cluster randomised trial. Across 3 regional and academic medical centre sites.	Patients (N=803) 51.4% of delirium rounds included research staff and unit champion Number of family carers not reported Patients with dementia and/or delirium	Weekly delirium rounds led by advanced practitioner nurse (N=750). Staff were encouraged to talk with patients and family members to learn more about hobbies, interests and occupation.	Analysis of delirium rounds over 38 months.	Not reported	Instances of person-centred care during delirium rounds.

Participant Characteristics

The definition of “older adult” ranged from 50 years and above. Not all studies reported participants’ ages. Bateman et al. (2016) specified participants were aged greater than 65 years or greater than 50 years for Australian Aboriginal participants. Dementia was diagnosed using a range of validated measures, including The Modified Blessed Dementia Rating Scale (MBDRS) (Fick et al., 2011), AD8 score (Boltz et al., 2015) and Mini-Mental State Examination (MMSE) (Bateman et al., 2016). One RCT (Martinez et al., 2012) reported a low incidence of dementia, 2-6% of the included patients within both groups.

Most studies (n=11) used interviews and/or observations and focus groups as data collection methods. Some studies measured patient outcomes and family caregiver outcomes (Boltz, 2015, Fick et al., 2011). Collier et al., 2020 used a video reflexive ethnography approach. Waszynski et al., 2019 measured median agitation scales. Mailhot et al., 2020 assessed clinical outcomes using a validation study. The randomisation to an intervention and data collected on effect in clinical outcomes was collected in three studies, Martinez et al., Goldberg et al., and Wasynski et al., 2019.

Person-centred care was the theoretical framework for one study (Yevchak et al., 2017) using discussion of delirium assessment and measurement of descriptive statistics. Mailhot et al., 2020 discuss a diagnostic bias which may have skewed estimated sensitivity and specificity Studies, n=2 used surveys, the intervention of a delirium brochure, Paulson et al., (2016), linked to a large multisite intervention study the Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD).

Most studies (n=10) used interviews and/or observations as data collection methods. Four of the studies used a family focused intervention (Boltz et al., 2015, Martinez et al., 2012, Mailhot et al., 2020, Wasynski et al., 2018). Of the 15 studies, n=5 reported using family dyads.

Results are presented in cross-cutting themes to reflect relevance to the review objectives rather than the frequency of the topic (Braun and Clarke, 2006). Studies explored non-pharmacological approaches using interventions to support patients with DSD that acknowledged the role of family carers.

Intervention Characteristics

Supportive interventions ranged from those involving family in keeping the patient active and oriented, to those that focused on staff knowledge including identification of people at risk, raising awareness of how family members could inform care, the admission process and ward environment (Appendix 7).

Some studies focused only, n=6 on people living with dementia (Ayton et al., 2018, Bateman et al., 2016, Boltz et al., 2015, Fick et al., 2011, Yevchak et al., 2017 and Teodorczuk et al., 2014). 5 studies described their inclusion participants as those with cognitive impairment (Blair et al., 2019, Collier et al., 2020, Goldberg et al., 2013, Kang et al., 2016, Wong Shee et al., 2014). Across all the studies out of a reported sample size of n=1353 of all participants that had dementia, cognitive impairment or confusion, of those n=376 with dementia. One study (Waszynski et al., 2018) described hospitalised older adults experiencing hyperactive or mixed delirium and receiving continuous observation, one study (Martinez et al.) described hospitalised patients at intermediate or high risk of developing delirium. Mailhot classified patients as with and without dementia.

Understanding the role of volunteers when supporting patients with DSD

Four of the studies interventions involved volunteers (Ayton et al., 2020, Bateman et al., 2016, Blair et al., 2018, Wong-Shee et al., 2014). A recurrent theme across the four studies was the aim for volunteers to address the difficulties hospital staff face providing person-centred delirium and dementia care. Wong-Shee et al., 2014 describe a volunteer mediated diversional therapy program for patients with CI (diversional therapy activities and number of visits provided are described in Table 9 below). Inspired by HELP, in Australia, the Volunteer Dementia and Delirium Care (VDCC) programme aims to provide help for emotional support (orientation, communication, therapeutic activities and a creation of personal profiles). The programme acknowledged the acceptability of the intervention but recognised the need to be further exploration around issues such as assisting with feeding and mobilisation. Volunteers were recruited as a proxy for a family member and, where appropriate, worked with a family carer. They were supported to engage in conversations to help orient the person, assist with feeding, hydration, mobilisation, use of visual and/or hearing aids, meaningful activities, and general encouragement for patients.

In summary while the development of such programmes appeared to have been implemented initially for staff benefit, *“took the heat off “, “met the need for increased care”.*

“*It highlighted the need for increased care and one-on-one. The increased care provided by the volunteers was exceptional, I believe complimented what we did well”* (Bateman et al., 2016).

While there were some occasional boundary disputes, staff accepted the volunteers and reported “patients more content” (Bateman et al., 2016). All staff reported patients had better care and better outcomes, highlighting the need for more staff or the reorganisation of staff to meet these complex needs. Across the four studies, the evidence suggests that volunteers can provide companionship and a sense of comfort by engaging patients in social activities but that it’s important to manage the expectations of the volunteers and staff who are expected to support them and ensure they are welcomed.

Table 9: Diversional therapy activities by volunteers

Activity	Visits (n = 298) N (%)	Patients (n = 30) N (%)
Conversation	298 (100.00)	30 (100.00)
Games - e.g. Connect 4, Hookey, Dominoes	43 (14.4)	11 (36.7)
Cards, memory	30 (10.1)	13 (43.3)
Jigsaws	54 (18.1)	14 (46.7)
Music	9 (3.0)	7 (23.3)

Understanding the role and value of staff education and training in supporting patients and their family carers with DSD

Five studies emphasised staff education and training to enable family engagement (Boltz et al., 2015, Kang et al., 2017, Mailhot et al., 2020, Paulson et al., 2016, Teodorczuk et al., 2014). Other studies included educational packages for nursing staff (Fick et al. 2011, Kang et al., 2017, Paulson et al., 2016, Teodorczuk et al., 2014 and Blair and Bateman, 2018, Boltz et al., 2015). One feasibility study tested a family-centred, function-focused care intervention (Fam-FFC); this involved staff education, environmental adaptations and a nurse to support family engagement in activities supporting nutrition, physical activity and cognitive stimulation (Boltz et al., 2015).
Paulson et al., 2016 and Kang, et al., 2017 described an educational intervention in the form of the development of a care giver focused delirium brochure. The goal of the brochure was to provide ideas of non-pharmacological interventions that could be delivered by the family carer. The study discussed that the brochure has a place and can enable family carers to deliver non-pharmacological interventions to support delirium care without direct nursing supervision.

The development of the study however did not involve family carers, and the implementation faced challenges such as lack of dissemination of the brochure despite being freely available.

The delivery of educational modules to detect DSD by nurses was part of a wider intervention of a computerised decision support tool for DSD in older adults, this pilot study (Fick et al., 2010) enrolled and followed 15 patients with dementia and their caregivers daily during hospitalisation. The study reported less than optimal attendance at the educational sessions therefore this influenced their attitude towards the intervention.

An educational intervention was also described by Kang et al., 2016, whereby nurses attended four workshops, sessions were carried out in the clinical environment and included patient scenarios, role play, discussion, lectures and self-directed study. The educational programme was delivered 4 times with 7-10 participants attending each time. Knowledge of nurses in understanding cognitive impairment was measured by using vignettes, using multiple choice and open-ended questions. The Korean version of the Facts on Aging Quizzes (FAQ) (23) was used to measure nurses' attitudes towards older adults; results are illustrated in Table 10 below.

Table 10 Comparison of attitudes towards older adults between pre-and post-intervention

Attitude towards older adults	Pre-intervention	Post-intervention	z	P
Positive bias	0.13 (0.16)	0.08 (0.13)	-3.000	0.003*
Negative bias	0.54 (0.19)	0.43 (0.19)	- 4.894	0.000*
Net bias	0.41 (0.29)	0.35 (0.25)	- 2.183	0.005*

Only four family carers were interviewed, and only two of those had a loved one with a documented diagnosis of dementia. The study acknowledged several limitations which included: lack of a control group, self-report questionnaires and interviews do not objectively measure outcomes, and there was a gap between what nurses said they did in interviews and what they were observed to be doing in practice. Most importantly, I consider the lack of evaluation of family caregivers and their integration and involvement in the educational programme was a missed opportunity.

The impact on health outcomes for patients with DSD following randomisation to an intervention

Four of the included studies compared the impact of the intervention on the health outcomes of the patients with dementia and the carer burden and well-being (Bateman et al., 2016, Goldberg et al., 2013, Mailhot et al., 2020, Waszynski et al., 2017). The impact of simulated family presence as an intervention on decreasing the level of agitation in patients with dementia was reported by Waszynski et al., 2017. The study identified a statistically significant difference (p=0.001) between family video (60%) and usual care (35.1%). Testing a specialist medical and mental health unit compared to usual care in a large acute general hospital in the UK was reported by Goldberg et al., (2013). Primary outcomes of this study reported there was no significant difference in days spent at home following discharge between the specialist unit and standard care (median 51v45 days; 95% confidence interval for difference-12 to 24; P=0.3 by Mann Whitney test. Specialist unit patients were more likely to return home from hospital (74% v 70%, 95 confidence interval for difference-3% to 11%), but for those who returned home, the number of days at home were similar (median 70.5 v 71 days, 95% confidence interval for difference 6 to 6.5%). Mortality in hospital was 29 (9%) versus 22 (8%). Specialist unit patients were slightly more likely to survive to 90 days (78 v 75%, 95% confidence interval for difference- 4% to 9%), less likely to move to a care home (20% v 28%, 16% to 0%), or to be readmitted (32% v 35%, 10%-5%).
Secondary outcomes identified those on the specialist unit had a significantly higher quality of hospital experience, more often in a positive mood or engaged (median 79% v 68%) or engaged in social interactions (47% v 39%), and less often in a negative mood (11% v 20%).

They experienced more staff interactions that met psychological and emotional needs. Family carers of patients randomised to the specialist unit were significantly more satisfied with the overall care experience; this included dignity and respect, nutritional needs and understanding the needs of the confused patient and discharge discussions. Health status outcomes, carer strain, and carers' psychological wellbeing were not different between groups 90 days after randomisation.

The ability of a family-rated Family-Confusion Assessment Method (FAM-CAM) delirium identification tool in the ED compared clinical outcomes in the 6 months after enrolment of the FAM-CAM status. ED visits and mortality rates were significantly higher among patients who screened positive on the FAM-CAM than in those who screened negative (hospital admission: 40% vs. mortality: 13% vs. 3%; ps < 0.05).

Bateman et al. (2016) evaluated the introduction of volunteer-led personal support for individuals experiencing dementia and delirium within an acute rural hospital in Australia. While the intervention was associated with a statistically significant reduction in patient length of stay, this outcome requires cautious interpretation, as concurrent increases in the administration of analgesic medications may suggest a shift in clinical management practices rather than a direct effect of volunteer presence. The reporting of only a single fall during volunteer duty periods highlights a potential contribution to patient safety; however, the limited incidence data constrains broader generalisation. Moreover, the reliance on tabulated outcomes for patients, staff, and volunteers underscores the need for more nuanced qualitative exploration of how such support reshapes relational dynamics and care experiences. Taken together, the findings point to the promise of volunteer engagement in acute dementia and delirium care, while simultaneously raising questions about sustainability, the interplay with pharmacological interventions, and the extent to which reductions in hospital stay reflect systemic rather than volunteer-specific factors.

Table 11: Patient Outcomes

Variable	**First 15 admissions (n (%)/mean, SD)**	**Last 15 admissions (n=1%) mean, SD)**	**P value (pre-to Post-program Difference)**	n^2
Analgesic	1 (6.70%)	6 (40.00%)	0.03*	0.28
Antidepressant	5 (33.30%)	6 (40.00%)	0.71	0.01
Antipsychotic	2 (13.30%)	1 (6.70%)	0.55	0.04
Benzodiazepine	1 (6.70%)	2 (13.30%)	0.55	0.04
Length of stay	19.27, 13.63	9.93, 5.22	0.02*	0.17
Patients who fell	0 (0%)	0 (0.00%)	NA	NA
Deaths	1 (6.70%)	1 (6.70%)	1.00	0.00
Delirium	7 (46.70%)	6 (40.00%)	0.72	0.01

*Significant at $p < 0.05$

NA, not applicable. SD, standard deviation

Table 12: Staff and volunteer outcomes

Respondent	**Questionnaire Item**	**Pre-program/ education score (mean, SD)**	**Post-Program/ Education score (mean, SD)**	**Post–programme Score (mean, SD)**
Staff	Carer stress	15, 3.0	15, 3.0	15, 3.0
	Attitudes – hope	31, 4.1	31, 4.2	31, 4.2
	Attitudes - person-centred care	42, 3.2	42, 4.3	42, 4.3
Volunteers	Knowledge	6, 1.0	8, 2.0	7, 3.0
	Confidence	21, 5.0	25, 3.0	27, 2.0
	Attitudes – hope	29, 3.4	31, 4.8	32, 3.6
	Attitudes - person-centred care	43, 3.7	47, 3.1	46, 4.0

SD, Standard deviation

Some of the included studies involved family members in as much as they were invited to provide feedback on the intervention.

Randomisation to interventions versus standard care

One RCT used video recording to simulate the family member's presence as a non-pharmacological intervention to reduce agitation in persons with dementia (Waszynski et al., 2018).

Waszynski et al., (2018) explored the use of simulated family presence (SFP) on the agitation level of hospitalised, delirious and acutely agitated patients. Family members were asked to pre-record a video message. Participants included in the study were those experiencing hyperactive or mixed delirium and receiving continuous observation (n=126), with 111 competing the study, of whom 67 had dementia. Participants were randomised to either view a one-minute family video message, a one-minute nature video, or usual care. The Agitated Behaviour Scale measured agitation prior to, during, immediately following, and 30 min following the intervention. There were small but statistically significant findings to support the use of family video messaging to decrease agitation, and evidence that a nature video was preferable to no intervention. The authors concluded that further work was justified to see if the positive results could be sustained.

Fundamentals of Care

One single site ethnographic study focused on the fundamentals of care to deliver high quality care for people with dementia and delirium. Fundamentals of care was defined as optimising sleep, hydration and nutrition, vision, hearing and cognitive and physical activities, combined with nursing staff knowing the patient sufficiently well to be able to anticipate their needs and communicate effectively with role modelling by the unit manager (Collier et al., 2020). Over an 18-month period within a specialist geriatric evaluation unit in Australia, using video reflexive ethnography, it explored how care based on these principles was provided. Qualitative findings suggested that creating a special space, involving nurses committed to the care of older people living with dementia, who listened to family members and a commitment to teamwork, were important. The authors argued it was the collective values and philosophy of the team, (rather than an individual’s actions) and the trusting nurse, patient and family relationships that were central to placing high value on and enacting high quality fundamentals of care. The transferability of the findings should be considered with caution as only 3 patients and 5 family members consented to participate, and findings reflected staff (n=40) accounts.

Discussion

The systematic scoping review assessed emerging evidence from 15 studies across 5 countries that reported on supportive interventions involving family carers with adults with or at risk of delirium superimposed on dementia (DSD) in acute hospital settings. The limited empirical evidence, relating to what interventions involving family support patients with DSD in hospital, fails to provide a broad degree of understanding of how family carers can be involved and integrated into part of the healthcare team with transferable guidelines and interventions.

The included studies were predominantly non-matched, quasi-experimental interventions. There was a range of intervention approaches that focused on educational resources, individual staff or whole system approaches. Limited studies reported in any detail on family carer involvement with some relying solely on family feedback. Most of the studies were clinically led with limited input from family carers or their representatives in the design.

The review findings demonstrated recognition of the importance of the family or their proxy as a way of supporting staff when providing care to people living with dementia with delirium. Although only two studies considered the quality or mutuality of the patient-family-carer relationship or how confident family felt to raise concerns (Boltz et al., 2015, Kang et al., 2017). Establishing how well family members knew the patient, who was best placed to be the key informant and the support family members needed to raise issues received little attention. Other studies have identified the importance of recognising who knows the patient best and addressing family concerns about causing staff additional work, (Abbott et al., 2022, Anantapong et al., 2022, Quinn et al., 2019). A recent review of nurses' experiences of managing delirium (not DSD) in acute care settings found nurses did not prioritise this work even though the evidence supports active prevention and intervention. They argued for organisational support to improve nurse awareness and practice (Lim, et al. 2022).

Regardless of the type of intervention, family appreciated having the opportunity to be involved. The studies with educational interventions increased staff knowledge of the patient and preparedness for caring for this sometimes-complex patient group, but how this led to improved outcomes was not demonstrated.

Further work is needed to understand how family involvement is planned and supported, and the resources that facilitate their involvement (educational materials, digital resources). A recurring issue in the literature was whether family involvement reduced demands on staff time. However, for the family to be adequately supported and incorporated into the working practices of the ward suggests this will require extra staff engagement with the patient and their family. The review reiterated the potential of involving family members in the care of people with DSD. However, there was minimal evidence of involving family in the study design or commenting on what was helpful.

The review findings demonstrate the benefits of involving family in acute care settings complements work on patient-carer dyads and relationship-centred working for older adults with dementia and their family carers in other settings reported by (Birkenhäger-Gillesse et al., 2020; Birkenhäger-Gillesse, et al., 2022). Both have shown the value of thinking about the patient-carer dyad and the need for further research to establish what kind of interventions are effective. It also raises further questions about staff knowledge and understanding of DSD and if this needs to be addressed first before involving family members (Soun et al., 2023).

The results of the scoping review have been used as a framework to develop the intervention phase of the study. An overview of what is known about interventions involving staff and family carers, that support the care of patients with DSD in hospital, has helped to locate gaps in the available empirical evidence, namely, how relationships between staff and family carers and relationship between volunteers and patients may support the patient with DSD in hospital and how this approach

Strengths and Limitations

This review included a systematic and thorough search of the literature relevant to supportive interventions involving family carers when providing care to patients with DSD in hospital. As such, it provides and underpins a foundation for future related research and practice. However, most of the studies did not report on carer involvement or evaluation of carer related interventions.

Potential limitations are recognised. For example, possible inadequacies in the search strategy: terminology varies across countries and professional disciplines which may have impacted on the studies retrieved. Additional search terms may have identified additional relevant studies that were not identified through the selected studies. The term delirium is still misunderstood, despite its origin in history, and often goes unrecognised when superimposed on dementia and has strengthened the need for this review.

Chapter summary

The limited empirical evidence, relating to what interventions involving family support patients with DSD in hospital, fails to provide a broad degree of understanding of how family carers can be involved and integrated into part of the healthcare team with transferable guidelines and interventions.

From the literature, there was a lack of exploration and understanding of the complex nature of DSD and how family involvement is planned and supported. A recurring theme in the literature was whether family involvement reduced demands in staff time. The review reiterated the potential of involving family members in the care of people with DSD. However, there was minimal evidence of involving family in the study design or commenting on what was helpful.

The purpose of the review was to inform the design and clarify the focus of Phase 2 of the study. The original study plan was to identify validated interventions or resources involving family carers and healthcare professionals in supporting patients with DSD in hospital. However, no financially viable sources or standard methodology to understand and facilitate a relationship approach to caring for patients with DSD and their family carers was identified. As Appreciative Inquiry has successfully been used in other hospital studies (Dewar et al., 2011, Merriel et al., 2022, Scerri et al., 2015, 2019, Watkins et al.,2016, 2019), it was selected as an appropriate methodology for Phase 2 of the study.

Chapter 3 - Methods

> *"We cannot solve our problems with the same thinking we used when we created them" (Albert Einstein)*

Introduction

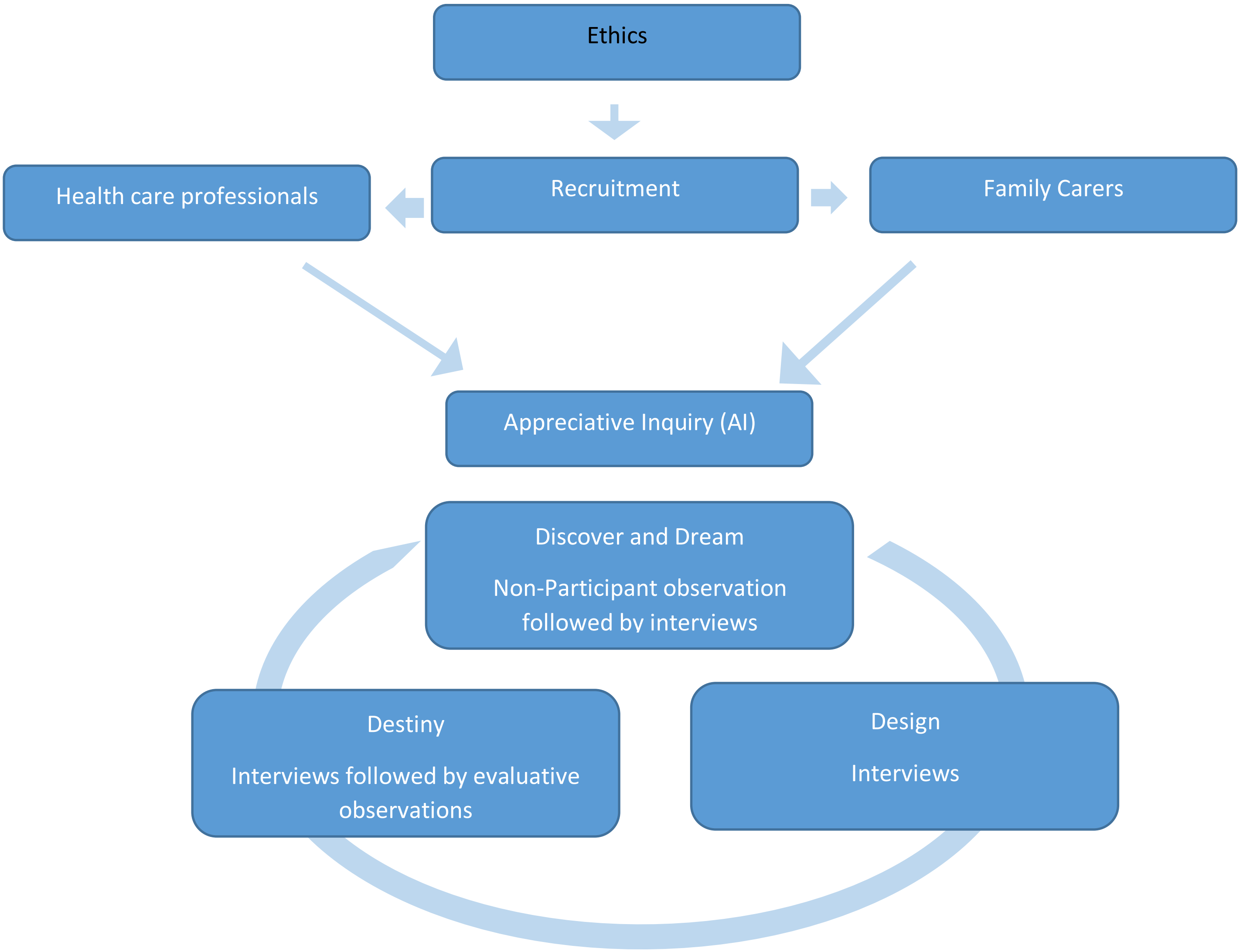
This chapter provides a rationale for the decisions and actions that was taken in building the study design, methodology, data collection methods and analysis for Phase 2 of the study (Figure 6). It is important to highlight that while Figure 6 includes Design and Destiny, these were ideas some participants raised in interviews, at times, in response to the interview question but they were not fully imagined in their entirety for this Doctorate.

Following the Phase 1 scoping review, the research questions were refined, which also reaffirmed the selection of Appreciative Inquiry (AI) as the methodological approach.

This chapter begins with an introduction to relational constructionism as the world view that underpins Appreciative Inquiry (AI).

The research questions and methods are discussed in the context of current and emerging hospital research and practice. Each element of Phase 2 of the study is then explained in detail; demonstrating why the methods were selected to answer the research questions, and how they were modified to meet individual and organisational needs. Specifics of the ethics process are also described to address the complexity of the consent processes required for participants living with dementia.

Figure 6: Phase 2 Study Design



Please note the Destiny and Design phases are demonstrated in the diagram as some participants began to discuss these, but they were not fully examined as part of this Thesis

Data collection was primarily organised to address the Phase One (Discover and Dream) and Phase Two (Design) stages of Appreciative Inquiry (AI). The study did not fully include the Design phase within its data collection scope for two reasons. First, time constraints restricted the ability to carry out comprehensive data collection, synthesis, analysis, and interpretation. Second, the Design phase required contributions from more senior stakeholders. Nonetheless, some participants shared preliminary ideas related to the design phase during their interviews. Future research will examine the Design phase in greater depth, and this focus is already integrated into the Trust's Dementia and Delirium Clinical Strategy.

Research Questions

The research questions for Phase 2 were developed from a combination of clinical experience working in hospital with patients with dementia and delirium, my role as a volunteer within the community supporting dementia friendly groups/community, my own personal experience of family members with dementia and delirium, the support I provide to family carers, and the results of the scoping review (Ashton-Gough et al., 2025).

The research questions were:

1. What is the evidence that supportive interventions that involve patients with delirium superimposed on dementia (DSD), family carers and healthcare professionals lead to improved outcomes for the patient and experience for the carer?
2. How do hospital staff involve family carers in recognising the signs and symptoms for delirium and providing effective care for someone with delirium superimposed on dementia?
3. Can a relationship-centred approach to dementia and delirium care be co-designed and provided by staff and family carers of patients in hospital with dementia?

Delirium Superimposed on dementia and Relationship Centred Care

For phase two of this study, the working definition of delirium superimposed on dementia drew on the work of Morandi et al., 2017 and Apold, 2018.

"Delirium is an acute neuropsychiatric disorder characterized by a disturbance in attention and awareness, which develops over a short period of time, with additional disturbance in cognition that are not explained by a pre-existing

cognitive impairment. Delirium that occurs in patients with dementia is referred to as delirium superimposed on dementia (DSD)" (Morandi et al., 2017).

Apold, (2018, pg.183) describes "Delirium superimposed on dementia is an underdiagnosed disease process associated with increased mortality and morbidity, longer recovery rates, higher cost, increased risk for falls, and long-term care placement*".*

Current models of person-centered and relationship centered care highlight the importance of "knowing the person" to attain a human connection, often defined as "being with" the patient (Dewing, 2004). However, as Dewing (2004) suggests, this highly skilled activity requires specific interpersonal competences rather than technical expertise (Schultz et al., 2007).

Relationship centred care is based on four principles (Beach, 2006):

- Personhood matters
- Affect and emotion are important
- Relationships do not occur in isolation, and
- Maintaining genuine relationships is necessary for health and recovery, and is morally valuable

Key to this study was to understand how involving staff and family carers in exploring the intricacies of DSD and how through relationship centred care for this patient group could be enhanced.

Therefore, it is an assumption of the study based on clinical experience and professional training that integral to diligent care for patients with DSD requires care that is relationship centered. Soklaridis, et al., (2016, pg. 130) explains RCC is a "A framework for conceptualising healthcare which recognises the nature and quality of relationships".

Appreciative Inquiry (AI)

It is increasingly recognised that the ability to place the patient at the centre of nursing work and foster collaborative approaches to nursing is shaped by the work environment and the organisational culture (Bamforth et al., 2023, Karrer et al., 2020, McCormack and McCance, 2016). A theoretical approach often adopted in the Relationship Centred Care (RCC) literature is Appreciative Inquiry (AI) (Soklaridis, 2016).

Appreciative Inquiry (AI) is a philosophy and methodology for studying and generating change in social systems through the identification of what people in that system identify to be good practice (Cooperrider and Srivastava, 1987). Like action research it emphasises a collaborative and participatory approach that pursues change for the future and takes appreciation of the contexts in which people work (Egan & Lancaster, 2005). Concerned with organisational dynamics and power, it works on the understanding that organisational context can shape the action and change, and the development of supportive relationships between the researcher and the participant is fundamental (Cooperrider and Srivastava, 1987; Meyer, 2000; Reed, 2007). Where it differs from other participatory approaches to research like action research is that a positive approach to the process of conducting the research is explicit and inquiry and intervention are not seen as separate (Cooperrider and Srivastava, 1987).

Cooperrider and Whitney (2005, p.8) have defined appreciative inquiry (AI) as the

> *"cooperative, co-evolutionary search for the best in people, their organisations and the world around them. It involves systematic discovery, taking a strength's-based collaborative approach to focus on what gives life to an organisation or a community when it is most effective and most capable in economic terms*" (Zandee & Cooperrider, 2008)

A further definition focusing on its holistic focus is described as:

> *"A theory and practice for approaching change from a holistic framework. Based on the belief that human systems are made and imagined by those who live and work within them. AI leads systems to move toward the generative and creative images that reside in their most positive core, their values, vision, achievements and best practices".* (Watkins & Mohr 2001, pp. 262)

AI seeks to blend practice, theory and experiential learning, alongside a collaborative approach to the development and exploration of practice, celebrating and building on what is working well. It facilitates a process of collective envisioning and engagement between all the people involved in bringing about change, a process characterised by participation in meaningful discussion. A research approach that is context sensitive and that actively encourages participants' engagement has the potential to be more effective, ethical, and impactful by fostering a more collaborative strengths-based approach to improve clinical outcomes. Nurses to be innovative and change practice rely on an organisational culture that can consider and accommodate change and disturbance of normal routine and is receptive of new ways of thinking and doing.

Five principles underpin AI, (Cooperrider and Whitney, 2001) (Table 13)

AI invites participants to share their own thoughts, stories and experiences of effective practice to create new and deeper connections. During the Discovery phase it enables participants, not only to reflect on what has not been good about the past, it enables them to look at the strengths, the positives and what is working well. This approach echoes a famous quote, popularly attributed to Aristotle, as used for the title of Wass' paper on Education:

"*To educate the mind, without educating the heart is no education at all"* (Wass, 2018, p.63).

The study used AI as a method to answer the research questions by identifying what is currently working well in the care of patients with dementia and delirium, what are the experiences of those family carers who are supporting patients with DSD and how staff and family carers work together. The AI approach was also chosen to explore with individual staff what strategies, techniques and experiences they have and may share with each other to enhance the lives of people with DSD in hospital. The AI approach informed the approach and structure of the semi structured interviews completed as part of the data collection process using emotional touchpoints (Dewar et al., 2010, Macbride et al., 2020, Smith et al., 2010).

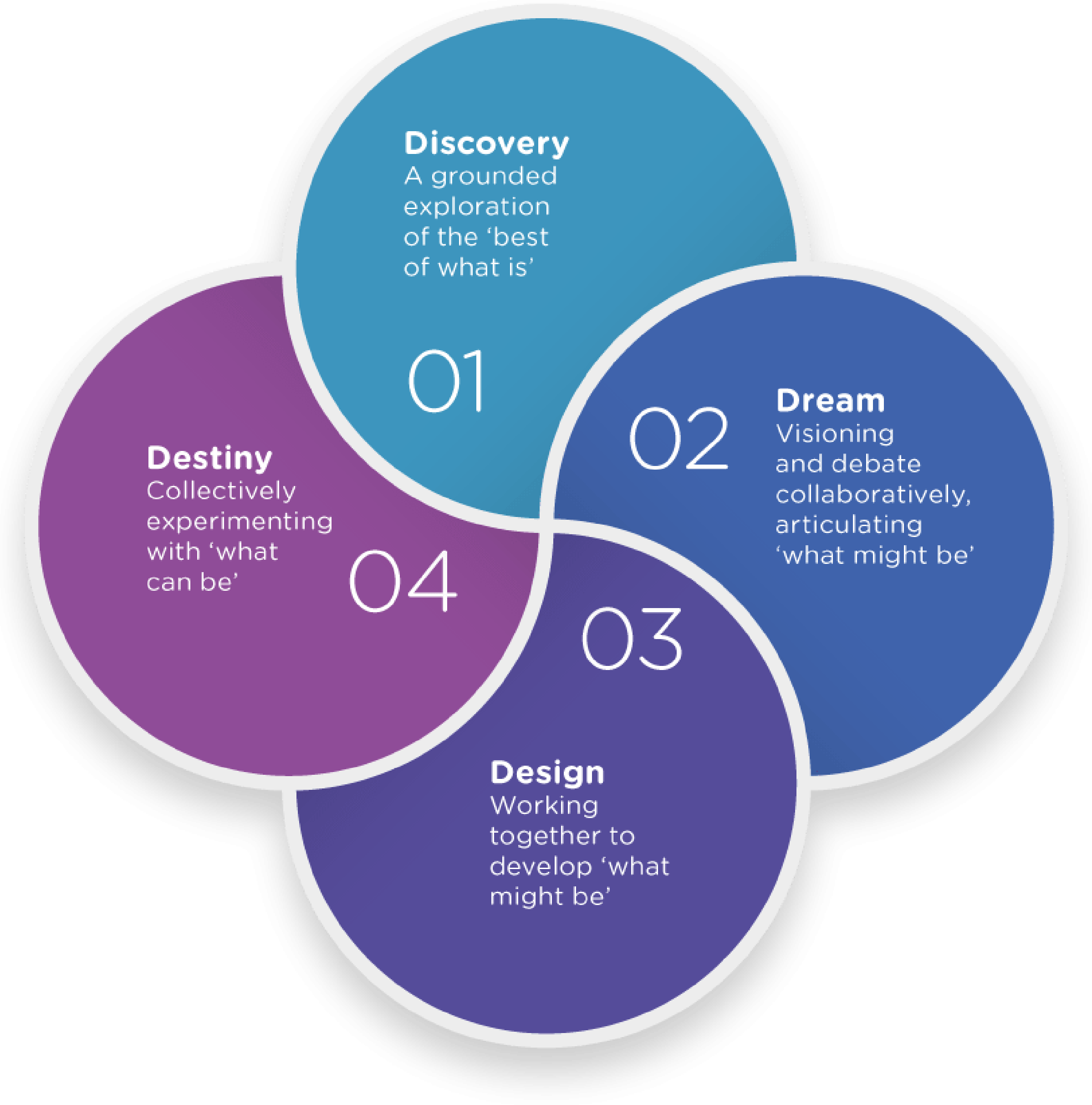
Table 13: Key principles of Appreciative Inquiry (Cooperrider and Whitney, 2001)

Five Principles of Appreciative Inquiry	
The constructionist principle	There is no single truth, different people understand the world in different ways. How a person understands the world and the language they use, determines how they think and act.
The Simultaneity principle	Inquiry and change are not separate and sequential stages, the questions asked, and the process of inquiry itself will create change.
The poetic principle	Storytelling is a way of gathering information that includes facts and feelings. Our stories change as we reinterpret the past. Words, sentiments and topics are co-authored and are the basis for creativity.
The anticipatory principle	The way people think about and imagine the future shapes the way they behave and move forwards.
The positive principle	By asking positive questions people are more deeply engaged and envision more bodily for a longer time, creating momentum for change, with hope and inspiration.

Developed as a quality improvement tool in businesses, there is some evidence of the efficacy of Appreciative Inquiry as a methodology to investigate, foster and change in clinical practice in in-patient settings (Merriel, 2022). Appreciative Inquiry (AI) has been used in care home research and healthcare studies as well as an organisational method for transformative change (Reed, 2007; Watkins et al., 2011 Watkins et al., 2019). In long term care settings for people living with dementia, Reed observed that the ethnographic component of AI provides a focus in making sense of contexts in a particular time and place, (Reed et al., 2008). Hospital employees have experienced AI's contribution to increased involvement in decision-making. Involving patients and families, encouraged the review of practices that were taken for granted, were challenged, replacing uncertainty with openness and confidentiality (Dewar and Nolan, 2013). Additionally, this approach enhanced sensitivity to cultural differences (Havens et al., 2006), as well as improved care for patients with dementia, when focusing on good exchanges between the healthcare provider and the patient (Scerri et al., 2015).

One of the most common AI processes used is the GEM 4-D Model (Watkins et al., 2011), (Figure 7), where participants address a chosen favourable topic though a dialogic process cycle of Discovery, Dreaming, Designing and Destiny (Cooperrider & Whitney, 2007). This structure will inform the observation and the approach to interviews using the Discover and Dream elements.

Figure 7: The 4D Cycle, Watkins et al, 2011



Hospital Preparation

Prior to introducing the study, it was important to understand how my workplace would respond. Implementation science, the scientific study of methods and strategies that facilitate the uptake of evidence-based practice and research (Glasgow et al., 2014), recognise that how an innovation is embraced is affected by an organisation’s history, priorities, culture, and context and its staff’s readiness to participate (Naveed et al., 2022). As a member of staff within the study site, I was aware of my own thoughts and feelings around this and had insight into what challenges there were likely to be. Engaging the Trust Board, the Research Department, senior staff and ward managers was a priority. I did not want them to think I was there to identify difficulties in care practice but, equally, I had to justify the need for this research study. I took part in the following presentations to staff groups:

- Research and Development Steering Group
- Senior Nurse Practitioner Forum
- Ward managers’ meetings
- Matron’s meetings
- Dementia and Delirium Steering Group
- Vulnerable Patient Group
- Patient Panel meeting

Questions raised at these meetings focused on how I intended to separate my professional role form my role as a novice researcher and how would I respond to patients, family carers and staff who asked for help, and how I would respond to noticing and supporting distressed patients. There was an interest and support for the study and recognition that this was a patient group who could be overlooked.

Using the 4D Cycle of Appreciative Inquiry

The ‘4D’ cycle fosters a positive and collaborative environment. It empowers participants to foster meaningful and sustainable change in their own community relying on the participants to contribute to multiple stages of the AI process. The four stages are explained here. Data collection methods at each stage of Discover and Dream are described later in the chapter ‘Data Collection Methods’.

Appreciative Inquiry (AI) has several strengths that make it a powerful approach for organisational change.

1. Allows participants to focus on the positive aspects, shifts the focus from organisational weaknesses to positive strengths. It facilitates people to focus

on the positive dynamics, improving organisational effectiveness (Cameron and Dutton, 2003).

2. It fosters creativity and inclusivity through the art of positive inquiry. It encourages a culture of inquiry that helps to create a shared vision and purpose by building on the organisation's core values and strengths (Whitney and Trosten-Bloom, 2010).
3. It helps to build on the core strengths of an organisation enabling individuals and the organisations to articulate its fundamental principles (Cooperrider et al., 2003).
4. It aims to achieve wholesome change that is recognised as likely to benefit every aspect of the organisation.
5. AI and the 4D cycle encourage individuals and the organisation to have conversations and make plans that create positive anticipation, facilitating behavioural changes required to achieve a better strength-based result (Ludema and Fry, 2008).

These strengths make AI an effective approach for motivating positive change clinical organisations that are oriented to improvement and maintaining quality of care. However, it is important to consider that the success is dependent on the context and its implementation. In synthesising the literature that describes AI, Dewar (2011), drew on the work of (Egan & Lancaster 2005; Cooperrider & Srivasta 1987, Moore, 2008 and Reed, 2007) and identified some key principles of working as an appreciative inquirer. They recognise the value of activities (feedback, a focus on the everyday, creating a sense of shared ownership of ideas).

I have added two more based on my own research experience, described in Table 14.

To further explore the two new elements that emerged from my Doctoral work:

- To be courageous, inquisitive and kind-demonstrated by participants at interview, examples of thinking differently around end-of-life care in dementia and going above and beyond to support family gave them a sense of pride and satisfaction in what can be a very emotional time and their frustration at others who may think differently.

- To provide opportunities to celebrate good practice and grow confidence in your team-demonstrated by the HCSW at interview and witnessed through non-participant observation, proud to demonstrate good practice and proud to share their knowledge with new members of the team. Sadly, some highlighted good practice and achieving positive outcomes may be frowned upon.

Table 14: Principles of working as an appreciative inquirer (Dewar, 2011)

- Working with the principles of what works well, rather than what are the problems

- Adopting a facilitative approach that encouraged participation and collaboration

- Enabling ownership - which sometimes means reinventing the wheel

- Asking curious questions which are essentially non-judgemental in order to get to the heart of what is going on

- A commitment to real time feedback to develop learning in a different way

- Recognising and working with relationships between staff, patients and families in the context of practice focusing on local everyday happenings

- Allowing the specific detail of the change to emerge over time and in response to the local environment
- Using creative and inclusive approaches to engage with people

- Developing knowledge in and for practice

- Analysing and reporting on the processes of inquiry which in itself is seen as an intervention for change

- Supporting people to take local actions forward, evaluate these and share experiences across the organisation

Dewar, 2011

- To be courageous, inquisitive and kind
- To provide opportunities to celebrate good practice and grow confidence in your team

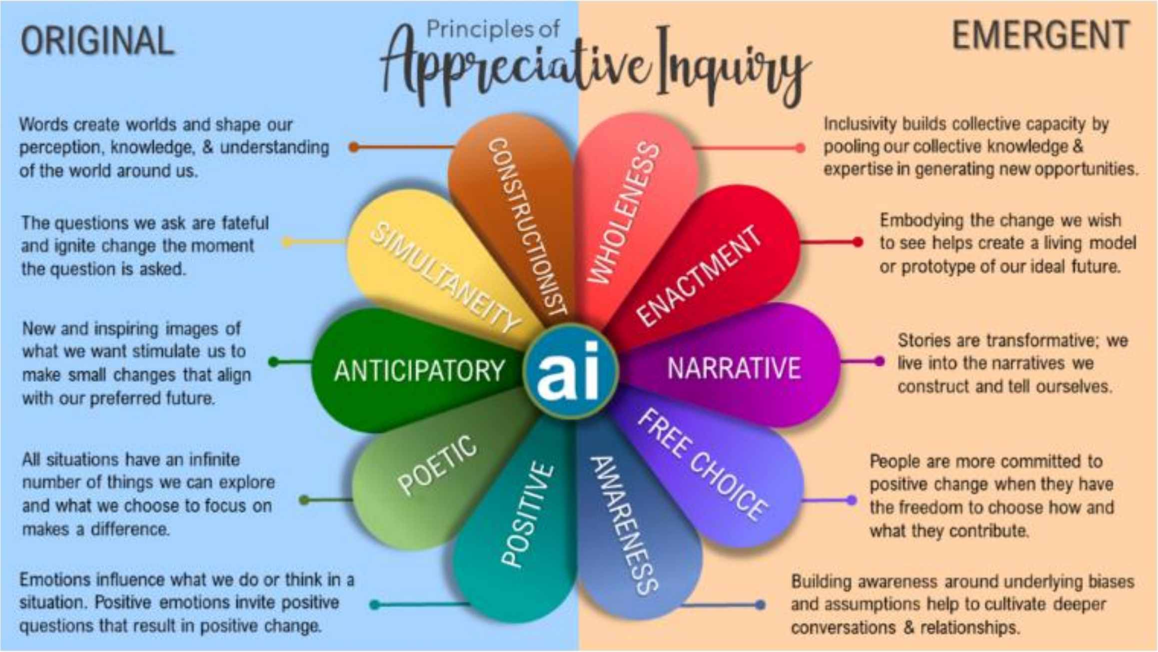
Ashton-Gough, 2024

Discovery

The Discovery stage of Appreciative Inquiry plays a crucial role in understanding and appreciating the positive features of a community or organisation. Unlike conventional problem-solving approaches, AI emphasises looking at **what's already working** rather than solely focusing on problems (Figure 8). During the Discovery stage, there is exploration of success stories and strengths, providing the opportunity to identify what is needed to sustain good practice (Smith, 2021). Additional principles that have emerged throughout the years, that are based on, or structured on, the original five principles and are described in Image/Figure 8 and build on the core tenant of positivity (The center for Appreciative Inquiry, last accessed August 2024).

Figure 8: Principles of Appreciative Inquiry

(The Center for Appreciative Inquiry, last accessed, November 2024)



Words create worlds and shape our perception, knowledge, & understanding of the world around us.

The questions we ask are fateful and ignite change the moment the question is asked.

New and inspiring images of what we want stimulate us to make small changes that align with our preferred future.

All situations have an infinite number of things we can explore and what we choose to focus on makes a difference.

Emotions influence what we do or think in a situation. Positive emotions invite positive questions that result in positive change.

Inclusivity builds collective capacity by pooling our collective knowledge & expertise in generating new opportunities.

Embodying the change we wish to see helps create a living model or prototype of our ideal future.

Stories are transformative; we live into the narratives we construct and tell ourselves.

People are more committed to positive change when they have the freedom to choose how and what they contribute.

Building awareness around underlying biases and assumptions help to cultivate deeper conversations & relationships.

A distinctive feature of Appreciative Inquiry lies not only in its orientation toward strengths rather than deficits, but also in its deliberate attention to what is currently working well and what has been effective in the past, prior to envisioning the future. Constructing a credible vision of a desired future necessitates grounding it in demonstrable achievements, thereby ensuring that aspirations are both plausible and contextually anchored. This process requires a systematic approach that acknowledges existing evidence, even when such evidence reflects only partial effectiveness, as it nonetheless provides a foundation upon which future possibilities can be meaningfully constructed. https://coachingleaders.co.uk/appreciative-inquiry-discovery/ (Smith, 2021).

This stage focuses on building relationships between participants, and this can be achieved through sharing stories, successes and identifying what looks and feels good, and what does good care look like for each participant (Bushe, 2011, Watkins et al., 2011). The emphasis on unconditional positive questions makes explicit what people value.

During this phase, extensive data collection took place to discover aspects of care that worked well on the ward to support patients with delirium superimposed on dementia as perceived by staff and family carers.

Dream

The “Dream” stage explores the themes that appeared in the “Discovery “stage and encourages people to explore beyond what is usually possible, (Cooperrider et al, 2008). It is at this stage the relationships and developing conversations provide the impetus to develop a shared narrative of what is needed and how that might be achieved. It draws on constructionist principles that reality is co-created by individuals and is ongoing (Nicholson and Barnes, 2013). The importance of conversations worth having is eloquently described in the quote below:

> *“When hearts and minds meet, they don’t just exchange facts and create atmospheres of hopelessness and despair, they transform them, reshape them, draw different implications from them, engage in new explorations of possibility. Such conversations are literally living systems, living on the edge of*

> *chaos and order……., like all life, when it is most alive, busting out all over with pattern and coherence but also alive with novelty and emergence"* (Stavros et al., 2022).

The challenge of this stage of the cycle is to move to a strategic focus based on facilitated conversations that reflect everyone's voices and understanding of what is needed across a system of care. It is not always clear in the literature how this is achieved or how facilitators take account of power relations, defensiveness and drivers within the organisation that will shape participants 'contributions (Watkins et al., 2011 and others). Participants' dream ideas inform the design stage of the process (Cooperrider et al., 2008).

Design

The Design phase of appreciative inquiry is an exciting and creative stage where people collaboratively envision and co-construct the ideal future. Overall, this phase is about laying the groundwork for adopting a positive, strengths-based approach to organisational change. It sets the stage for engaging stakeholders (staff and family carers), gathering insights, and co-creating a vision for the future based on the organisation's strengths and possibilities. The participants are therefore encouraged to explore the "Dream" ideas in the context of the discovery stories. During this stage a strength of AI is the Co-design phase (based on participatory action research assumptions), it is considering what might work, securing the commitment and involvement of key people within the organisation and project planning and management. Collaborative planning is essential and ensures that plans are inclusive and consider diverse perspectives. Individuals, or small groups of participants, develop plans to implement the ideas that they have dreamt and designed (Bushe, 2011, Cooperrider and Whitney, 2005, Watkins et al., 2011). By highlighting the strengths and resources within their teams and departments, staff can help shape the design of initiatives that capitalize on their assets (Watkins et al., 2016).

During this phase, while focusing on strengths and positive aspects can be empowering, there is a risk of real and significant issues being overlooked and there may be lack of critical analysis. The approach may not encourage challenge of existing assumptions or analysis of proposed ideas; there may also be resistance to change if participants consider their ideas will be ignored. How well this is navigated by those involved will be reliant on resources and organizational culture (Merriel et al., 2022).

While this study did not explore the Design stage as part of data collection, some participants did share ideas with the interview stage. Future work will explore this in more detail and is already embedded with the Trust Dementia and Delirium Clinical Strategy.

Destiny

Destiny is the final stage of the 4D cycle and provides the opportunity to implement and sustain the coproduced ideas. The Destiny stage was originally called Delivery (Cooperrider and Whitney, 2005) but was replaced to create a conceptual difference from the language and traditional assumptions of change management theory (Clouder and King, 2015). In his 2011 work, Bushe (2011) describes this stage where the participants collectively envision and design the future they desire. He describes it as provocative propositions-statements that challenge the status quo and articulate a bold vison for the future. He discusses how" Dreams and "Designs" could be used to create targets and objectives, which contradicts the AI philosophy, and the goal is to embrace the principles of participation so that individual contributions are acknowledged and valued. Watkins and colleagues (2016) emphasise that measures, standards and benchmarks can be integrated into AI, although the evidence suggests this is rarely the case (Amador et al., 2014) and can detract the participants from leading the process.

Outside of healthcare, the benefits of appreciative inquiry have been widely examined and include increased profits, reduced absenteeism and improved customer service (Bushe, 2011, Cooperrider et al., 2008). Appreciative inquiry in the healthcare setting is less well documented (Richer et al., 2010), although its popularity is growing (Smith & Plunkett, 2019, Watkins et al., 2016). Reviews of the AI literature suggest that it has been well received in health and social care and has resulted in successful implementation (Trajkovski et al., 2013, Watkins et al., 2016, Sharp et al., 2018).

A systematic review (Merriel et al., 2022) identified that there is minimal empirical evidence to support the effectiveness of Appreciative Inquiry in improving healthcare outcomes. However, they reported the qualitative and observational evidence suggested that AI may have a positive impact on clinical care resulting in improved patient and organisational outcomes. While this research did not intend to complete the 4th stage of AI, that of Destiny, it will be considered going forward in recommendations. The researcher acknowledges that this stage may be often the most difficult to complete. The real-world constraints of doing research in acute care settings limit how much change can be achieved in one doctoral study. Therefore, it is so important that the ideas within the destiny phase can be carried forward by the organisation and that it is given the respect and attention it requires. Whilst many descriptions of AI are keen to demonstrate only the positive aspects and outcomes, research suggests transformational change will not occur from AI unless it recognises and addresses problems of real concern to organisational members (Bushe, 2010, Bushe, 2011).

Using Appreciative Inquiry in the acute hospital setting

Appreciative inquiry has been used to facilitate practice change in several studies in acute hospital settings. For example, Dewar and Nolan (2013) used appreciative inquiry to work with older people, relatives and staff on older peoples' wards in acute hospital settings to create the 7Cs of caring conversations (Appendix 8) to support integrating relationship-centred care in clinical practice. Kavanagh et al., (2010) also used appreciative inquiry in their research about pain management for paediatric inpatients admitted to a surgical unit. Watkins (2019) used Appreciative Inquiry to discover the experiences of family members and nurses caring for older patients in the emergency department and improve outcomes such as relationship centred care. Scerri et al., (2019) used AI to implement person-centred dementia care in hospital wards using workshops, staff worked collaboratively and small changes in improved dementia care practice was observed.

AI in this study was used to structure data collection and analysis in the discovery and dream phases of the 4D cycle with findings being used to inform recommendations for practice and future research.

Ethics

This section considers the ethical issues that arise from carrying out research with people living with dementia and how they were managed in this study. The protocol and all supporting documentation for the empirical stage of the study was reviewed and approved by the HRA and Health and Care Research Wales (HCRW) ethics committee, (REC reference 22/EE/0144) (IRAS project ID 280075), (Appendix 9). An overview of the focus of the ethics application, gatekeeper's roles in protecting individual participants, approaches used to gain consent for non-participant observations of people with dementia and delirium, and how interviews with family carers and people with limited or fluctuating capacity to consent were organised.

Hospital

For people living with dementia admitted to hospital, there are ethical challenges associated with securing informed consent, ensuring privacy and confidentiality (Hall et al., 2009, Zermansky et al., 2007, Zermansky et al., 2006) and the prevention of harm or distress. Dewing, (2008) describes, "for persons with a dementia, informed consent becomes increasingly redundant and consequently exclusionary to them as person p.59". She argued for the use of a model which can strengthen the assent process (Table 15).

Table 15: The Process Consent Method (Jan Dewing, 2008)

The Process Consent Method
Background and preparation
Establishing the basis for capacity
Initial consent
Ongoing Consent monitoring

The ethics application addressed confidentiality, access and consent processes and the risk versus benefits ratio. These features were considered in the context of legal frameworks and ethical guidelines (Hall et al., 2009).

The principle of patient autonomy is strongly embedded in western philosophy and ethics and is increasingly accentuated in clinical practice, professional ethics, and health legislation (Beauchamp and Childress, 2013; Page, 2012). The principle justifies the moral rule that HCP should provide help based on the patient's consent.

For the person with dementia in hospital, assessing their capacity to consent to participate in research can be challenging. Staff often may not know the patient; the patient may have been moved wards frequently and therefore understanding the patient's level of capacity requires careful review. When impacted by delirium, this brings additional challenges. My role as a researcher, particularly during the non-participant phase, was to ensure my research was conducted under the framework of MCA as specified for research. The ethics committee that reviewed my application has specific expertise in studies where participants may lack capacity.

The National Dementia Strategy (Department of Health, 2009) and the Mental Capacity Act 2005) (Department of Constitutional Affairs, 2007) actively promote the inclusion and participation of people living with dementia in research. Historically, people with dementia are under-represented in clinical research, in part due to the ethical and legal complexities of involving people in studies who may lack capacity to consent (Davies et al., 2014, Dewing, 2002, Edvardsson et al., 2017, Liamputtong, 2006). Excluding this population from research limits the evidence to inform care (Ries et al., 2020; Silva et al., 2020).

Studies with vulnerable people in hospital place an additional level of responsibility on health and social care researchers in relation to the potential for diminished autonomy or reduced abilities of participants to make appropriate and informed decisions (Liamputtong, 2006). This responsibility can have a serious impact on researchers, leaving them feeling ethically and methodologically insecure (Dickson-Swift et al., 2007, Sherry, 2013). Clinical and academic supervision was timetabled and accessed throughout the data collection period to mitigate any detrimental effects on me as a practitioner and novice researcher.

The protection of an individual's privacy and confidentiality, and minimising intrusion, were crucial for this study. To ensure these ethical issues were thought of data was only collected in shared spaces within the hospital setting (for example, 4-6 bedded and open areas such as nurses' stations and corridors). A shared space in a hospital in this example is where clinical care may be given, in close proximity with other patients, but can be considered a public space on the ward. I did not enter single rooms and avoided observing intimate/personal care.

I was mindful that patients and their family carers' acceptance of my presence could have been misconstrued (Department of Constitutional Affairs, 2007). At the beginning of each observation period, I explained the purpose of my presence, I ensured I had prepared and received a brief handover from the nurse in charge prior to observation periods. I was aware of patients who may be approaching the end of life and avoided those areas. Staff and visitors present were asked if they were happy for me to observe them. There were also copies of the Participant information sheet presented in a poster (Appendix 10) on the ward explaining the study. This information was repeated for anyone newly entering space and existing participants if they questioned my presence at any time during an observation period. If, when observing the individual or area (as appropriate), it was evident my presence was causing discomfort or distress (e.g., agitated behavior or verbal comments directed at me) then I stopped the observation.

I specifically sought wards that by background were a care of the elderly/medical ward initially but also took care to incorporate visits to the wards such as Surgical, where post op delirium may have been more significant. Prior to each planned visit, which had been communicated with all relevant people, I called ahead to ensure it was OK to go ahead. This was important because acceptance of innovations is likely to be improved when contextual factors, such as culture and leadership, are considered. Despite being a member of the Trust staff, I did not take it for granted that staff would accept my research work.

Consent processes

The REC assesses the ethical competence of the research team and the rigour of the proposed study (Health Research Authority, 2017b). Although the ethical review framework cannot predict difficulties which could arise during fieldwork (Fahie, 2014, Holloway and Galvin, 2023), it can assess the perceived understanding of ethical awareness and capability of the researcher in the field. This process, alongside the introduction of the MCA (Department of Constitutional Affairs, 2005) and Deprivation of Liberty (DOLS) has supported safe access to people living with dementia in hospital. In England, proxy consent is not accepted (Department of Health, 2008).

The ward managers and matrons for the areas acted as gatekeepers and, alongside me, the researcher spoke of the study at ward handovers, safety huddles and ward manager. The gatekeepers were assured that any safeguarding related disclosures raised would be communicated and dealt with as per local Trust policy.

Consent was interpreted to mean that the participant/participants understood that they were taking part in a research project, what it may involve, how confidentiality would be managed, their right not to take part or withdraw their participation, and that the research outcomes would be shared. Study information and consent forms were presented in a variety of formats (Appendix 12) and multiple consent processes were used to promote inclusivity and choice. The processes for obtaining consent can be seen in Table 15.

Table 16: Consent processes employed

Consent Process	Participant living with dementia	Hospital participant	Family Carer Participant
Opt-out (observations only)	√	√	√
Ongoing informed consent	√	√	√
Process Consent	√		
Consultee assent	√		

Consent to participate by all participants (patients with dementia, family carers and staff), or assent from their consultees where patients are considered to lack capacity to consent, were informed, voluntary and ongoing.

Written study information provided a minimum of seventy-two hours before inviting people to consent to participate and was supported by face-to-face discussions with potential participants. Participant information sheet (appendix 11) was formatted with a large font with accompanying illustrations to facilitate understanding. These were reviewed at a local Dementia friendly coffee morning and by the hospital patient panel. All participants and consultees were made aware that it is their choice to take part in the study and it would not affect clinical care, working relationships or employment. Participants were informed they could withdraw from the study at any point. Additional considerations for consent are discussed below in relation to the participant group.

Information posters and leaflets were available on every unit in each patient area, each shared space, i.e. corridors, outpatient areas, staff rooms and meeting rooms. Securing consent depended on the individual participant's ability at the time and the data collection method. For example, some participants did not participate in interview but were observed (this may have been visitors/family carers). The approach to consent for this group involved introducing myself, signposting the participant to the information poster, providing a participant information sheet and checking understanding.

It is widely reported that researchers working with people with dementia must be fully trained in assessing capacity (Hubbard et al., 2003, Jayes et al., 2022) and Dewing (2007) identifies concern about the ability of novice researchers to apply complex consent processes. As a qualified nurse of twenty-nine years with an MSc in Advanced Care in Dementia, where my role frequently requires me to assess people's capacity, my knowledge, skills of mental capacity assessment and reflective practice prepared me for the process. Observations were carried out on an 'opt-out' consent basis (Lawton, 2001, Martin and Younger, 2000).

Ensuring that people had the option to withdraw, or not to be observed, relied on my assessment, which was on-going and required a good understanding of a person's body language and general well-being and whether this indicated discomfort. It also relied on individual and staff feedback on people's responses and behaviours linked to my presence (Dewing, 2007, Handley et al., 2020).

I utilised staff members' expertise and knowledge of individuals to support my assessment as to whether the patient had the capacity to provide consent at this time for the purpose of non-participant observations. I discussed participation directly with the patient, if possible, and conversations were ongoing only about their participation with staff or their family carers if they wished me to do so, or if I had reason to doubt their ongoing mental capacity regarding their participation. The MCA was used as a legal framework throughout.

Informed consent was gathered from all participants who had the capacity to provide it for interviews. Consent was accepted verbally as well as in writing.

Patients with dementia

This patient group is particularly vulnerable due to their declining health, declining cognitive abilities and age-related difficulties. In hospital there is also the added risk of developing delirium and the impact on cognitive decline. The ethics protocol application considered the potential to interview patients with DSD who may understand questions and have the capacity to consent, albeit a small number, but it was decided that it was likely they would be too unwell for interview. This was substantiated within my research, and the outcome was that there was no suitable PLWD to interview. The consent process for patients with dementia met the requirements of the Mental Capacity Act (Department of Health, 2005), in that capacity to consent was assumed unless there was evidence to the contrary. Patients were considered to have capacity to consent when:

- The person understands the purpose of the research.
- The person understands what their involvement in the study entails.
- The person understands they have the right not to participate, and this decision would not affect their care.
- The person was able to retain the information about the study and use it to inform their decision of whether to take part or not.

Process consent (Table 16) was used to offer people living with dementia and limited capacity, the opportunity to be involved and included in the research that previously may not have been considered achievable (Dewing, 2007, Dewing, 2008).

Table 17: The Process Consent Method-Taken from Dewing (p. 62-63, 2008)

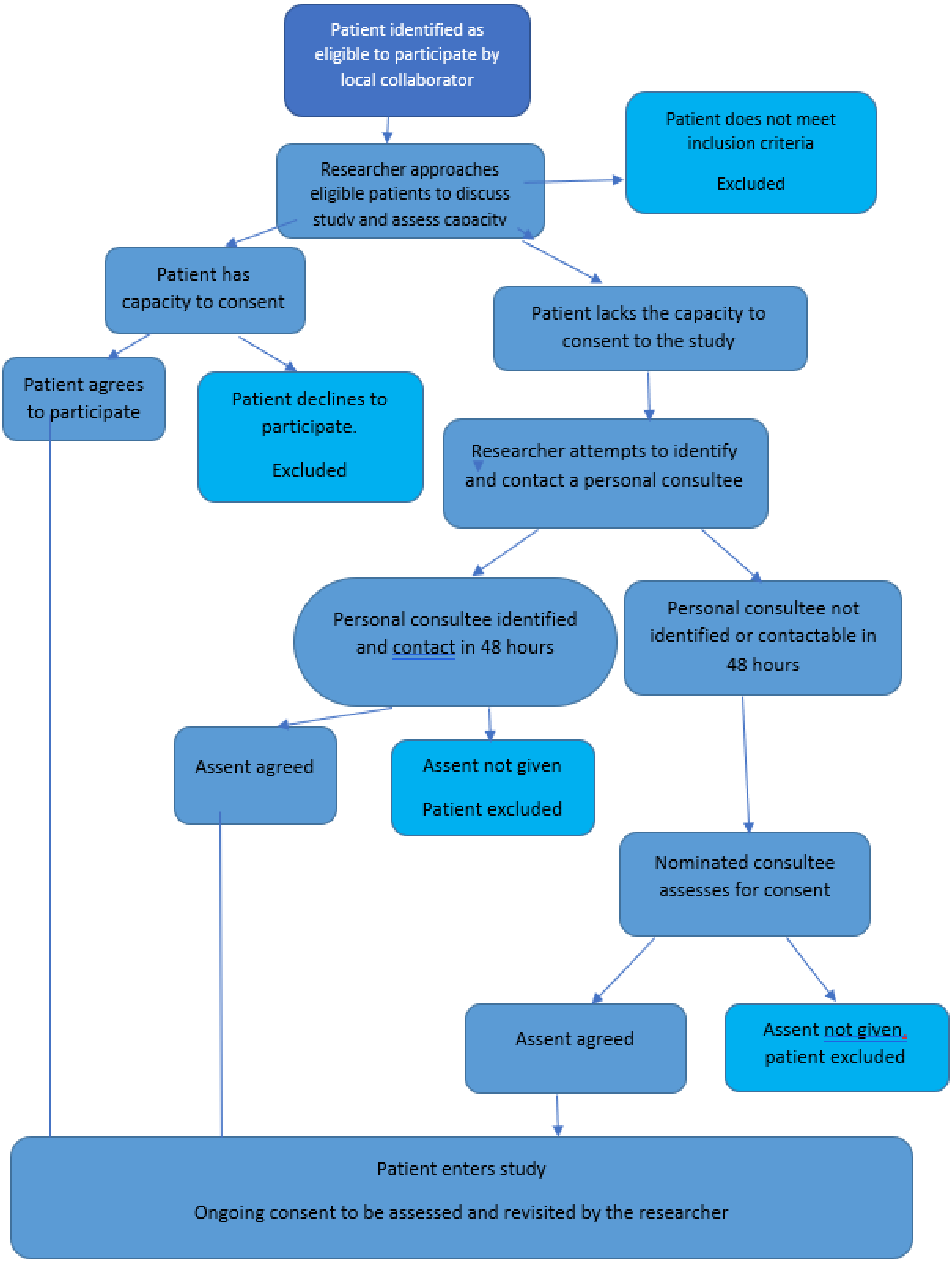
The Process Consent Method	
Stage One: **Background and preparation**	The researcher engages with gatekeepers to confirm access. This enables representatives authorised by the person living with dementia to be instrumental in the process. The researcher should be transparent about negotiations throughout. A basic biography of the person including a description of facial expressions or behaviours generally exhibited supports the ongoing process.
Stage Two: **Establishing the basis for consent**	The researcher engages with gatekeepers to confirm access. This enables representatives authorised by the person living with dementia to be instrumental in the process. The researcher should be transparent about negotiations throughout. A basic biography of the person including a description of facial expressions or behaviours generally exhibited supports the ongoing process continuously.
Stage Three: **Initial Consent**	Consent is specific to the individual. The individuals' communication needs and abilities are assessed, and information is modified to be meaningful to the individual.
Stage Four: **Ongoing consent monitoring**	Consent must be revisited and re-established on, and within, every interview or focus group. The ongoing consent may be assessed against the initial consent for consistency and transparency.
Stage Five: **Feedback and support**	If feedback to care partners, staff and/or supervisors is considered necessary, confidentiality needs to be carefully considered. Feedback should always be agreed with the person living with dementia beforehand if possible.

Confidence in informed consent

Mulhall (2003) discusses how confidence in informed consent of those being observed is difficult. Every opportunity was taken to inform patients of the purpose of the study and my role; I had considered that some patients would lack understanding, or the ability to retain the information. Ongoing consent was used to assess patient consent to observations.

Pressure to consent due to concerns about the impact on care was minimised as I was not a regular member of the ward team. However, if this was a concern, this would be discussed with my research supervisors, the nurse in charge and the local RD team. It was made clear to staff that they did not have to participate in the research; that their participation will be voluntary and will not impact on their role or the patients they care for.

Figure 9: The Consultee Process



Each patient identified as having dementia, and with suspected delirium, was identified by the nurse in charge (NIC). Given the nature of the research environment and often the frailty of the person with dementia, I clarified with the NIC if there were any areas or rooms that I should avoid. I considered using the Quality of Life in Alzheimer's disease (QOL_AD) questionnaire (Logsdon et al, 1999) to familiarise myself with the patient before carrying out non-participant observations. Assessment of quality of life may have given me more insight into the level and meaning of the person with DSD and their potential distress which would include physical, mental, social and functional aspects and this is thought to be acceptable for moderate to severe dementia (Brown et al., 2004 Hoe et al., 2009). However, given the constant changing nature of the environment, turnover of patients and clinical acuity, I felt that this would deter me from truly embedding myself in the non-participant observations.

Recruitment

Inclusion Criteria

Recruitment was influenced by the assumptions of the AI approach and the resources available for the study. This meant that choosing the number of wards visited was a pragmatic decision influenced by the number of hours the researcher had identified that was achievable and would capture the range of experiences and activities at different times, people with DSD experience while on a ward. A starting point for an invitation to participate was if an individual ward or manager was enthusiastic about the study.

Inclusion criteria (Table 17) were designed to include research participants most likely to be involved in or having experienced DSD in hospital. Exclusion criteria were: The Local Authority or the NHS Trust requesting exclusion on safeguarding grounds, people considered to be at the end of their life by the ward staff, and staff or family carers if considered necessary on safeguarding grounds.

The inclusion criteria reflected the research questions, namely, to include people living with dementia and those who had a diagnosis or suspected diagnosis of delirium superimposed. During the non-participant observation phase, I also considered how people with dementia observed as participants may also have communication difficulties. All forms of dementia are known to affect both expressive and receptive language abilities, including behavioural impairments and delirium that affect communication (Banovic et al., 2018, Bourgeois et al., 2010, Suarez-Gonzalez, 2021). This ultimately impacts on the person with dementia's ability to form and sustain therapeutic relationships often due to lack of staff awareness and anxiety, and lack of knowledge for family carers. Pepper and Harrison Denning, (2023), discuss verbal communication is a powerful tool when it comes to forming relationships, however often as dementia advances communication becomes lost and expression of needs and emotion becomes difficult. The scoping review (Ashton-Gough et al., 2025) showed that supportive interventions that enhanced the care of a person with dementia when experiencing delirium was enhanced by care that is relationship centred.

The study was organised across inpatient ward settings within one 501 bed District General Hospital (DGH). The study has been discussed with senior management and the Research Department. Ethical approval via NHS was given (280075/22/EE/0144, Appendix 9).

Most medical and surgical wards have 28 beds and approximately 40 permanent nursing and support staff working with a primary consultant team. They each have approximately 100 in patients per month.

Staff and family carers of people with dementia on participating wards were invited to take part in this study.

Table 18: Inclusion Criteria for Participants

	Inclusion Criteria
Hospital ward	To be eligible for the study the ward must: • Be an inpatient ward setting. • Regularly care for patients with dementia and/or delirium.
People living with dementia and/or delirium	People living with a dementia diagnosis and those identified by ward staff as displaying symptoms consistent with dementia, excluding PLWD at the end of life • Dementia with delirium superimposed. • Have been admitted to the inpatient ward in the acute hospital setting. • Have a diagnosis of dementia. • Do not have a formal diagnosis of dementia recorded in the medical notes but have been identified by staff or family members) as having dementia. Have a diagnosis of delirium.
Family Carers	The family carer must be a relative or close friend who regularly provides carer support and frequently visits.
Health care professionals	• Work within the inpatient ward setting. • Not a permanent member of the ward team but regularly works across all wards as a paid member of NHS Professionals or other nursing agencies and who regularly work with patients with dementia and delirium. • Are not based on the ward but who regularly work with patients on the ward or who have been caring for people with dementia as part of their work (for example mental health liaison nurses, palliative care specialist nurses, speech and language therapists, dieticians, physiotherapist. • Student nurses while on placement.

Recruitment of participants

To understand the potential population eligible for inclusion in the study a recently completed inpatient audit at the study site of 314 beds, found 64 patients had a confirmed diagnosis of dementia. The highest number of patients with dementia in one ward was 14/28 beds. Approximately 49 (76.5%) had a known delirium either on admission or during inpatient stay. There is likely to have been many more unreported hypoactive sub-types and patients also waiting or suspected of a dementia diagnosis. This has informed recruitment and data collection plans.

Staff

There are approximately 797 staff employed working on adult general wards (excluding theatres, intensive care, ambulatory settings and paediatrics) at the study site of whom 432 are qualified nurses and 195 are working as Health Care Support Workers (HCSW). To understand how different staff provided care and work as members of multidisciplinary teams, the aim was to recruit twenty staff members. The sample included Registered Nurses (RN), Health Care Support Workers (HCSW), Doctors and Allied Health Care Professionals (AHP) working across inpatient ward areas. Ten staff were finally interviewed, and this did not include any AHPs. Staff were notified of the study at a series of staff meetings, through the hospitals email system, daily trust's communication updates and through information leaflets left on wards to invite expressions of interest. Staff were recruited to participate in observations and interviews when they expressed an interest in taking part.

Family carers

Based on the projection from the audit of there being approximately 40 inpatients with dementia at any one time in the hospital, the aim was to recruit up to twenty family carers who are visiting the ward on at least two occasions. It was hospital visiting policy during the pandemic that people with dementia can have visits and support from family carers.

It was recognised that it may be difficult to recruit family carers when they are visiting hospital. These interviews were also supplemented with interviews with carers who have had recent experience of supporting someone at the study site with delirium. They were recruited through the local Dementia Action Alliance/Dementia friendly community, visitors to the trust through internal advertising, through the Integrative Care Board (ICB) and Carers support such as Carers First.

Risk

There were multiple risks to the study:

- Uncovering harm being done to patients.
- Ethical and legal challenges.

- Informed consent - ensuring informed consent is a significant challenge when there is flotation capacity, undertaking non-participant observations also provided an understanding of how staff approached this when delivering care.
- Assent and Dissent - even if legal consent is confirmed, it was important to ensure assent and dissent, meaning if a patient showed signs of distress or unwillingness to participate their wishes should be honoured. I believe my skills within my professional role on noticing distress in people with dementia strengthened my ability to ensure this was upheld.
- Emotional and psychological impact-research activities can be distressing for people with dementia. The risk in this study demonstrated as greater for family carers when expressing emotional concerns. For myself as the researcher but also as the specialist in this area.
- Privacy and Confidentiality - there is a potential risk of unintentional breaches of confidentiality.
- Physical health risks - rapidly changing clinical status, a real time example of this was when observing a patient, he started to decline rapidly and started to both vomit blood and required me to intervene.

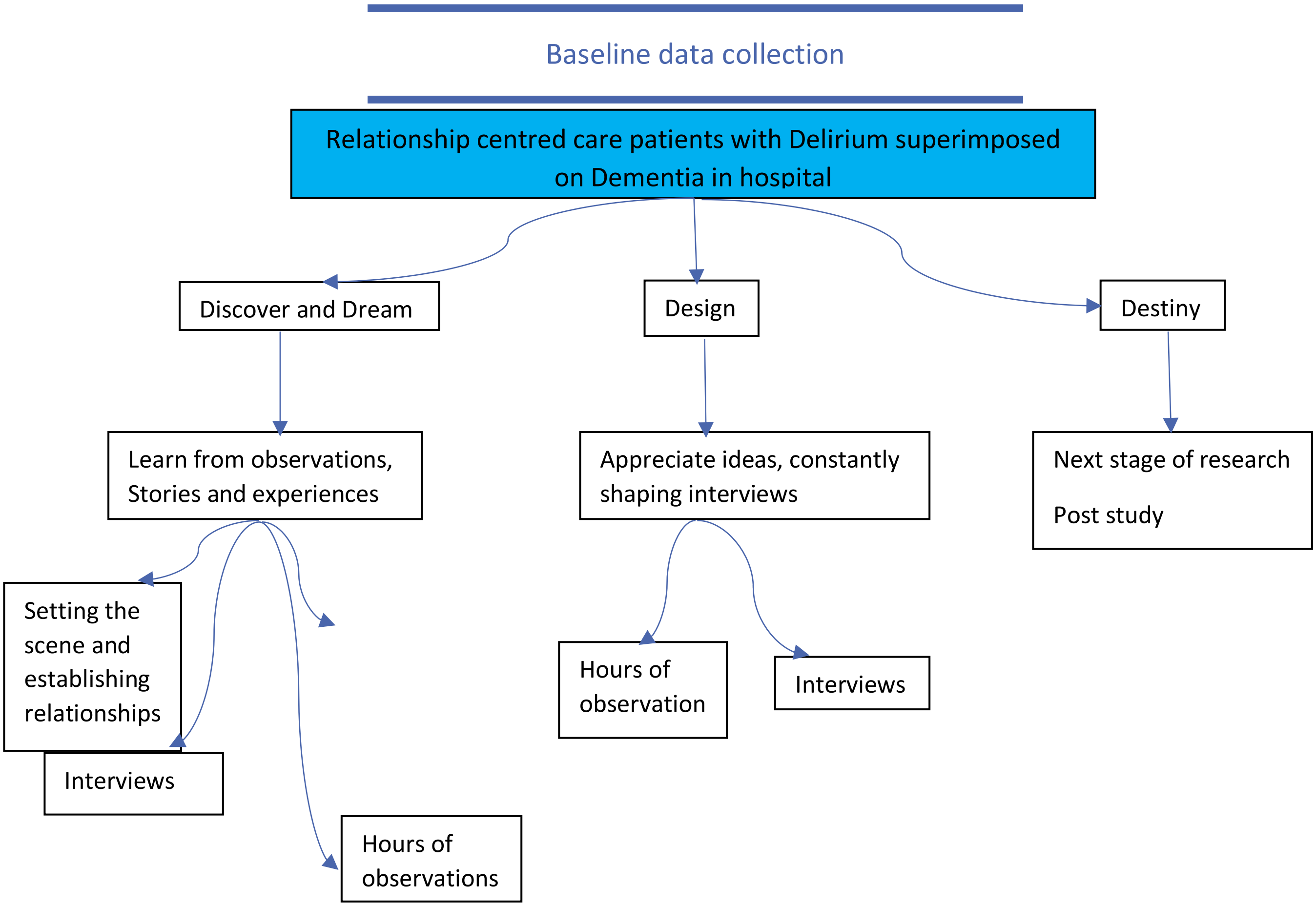
Key issues that had the potential to impact participant safety included: language, gatekeepers, the research relationship, communication, dealing with distress and researcher skills (Novak et al., 2017). It is possible that the findings will focus on what works and will uncover examples where practice could be better. There is a risk this could affect staff feelings of self-worth and confidence. All participants will have had the opportunity to debrief, and the overall research approach should mitigate this potential risk.

Data Collection Methods

The data collection involved non-participant unstructured observations, semi-structured interviews using emotional touchpoints, and participant engagement throughout the AI cycle. I wanted to enhance inclusion of as many different perspectives and 'voices' as possible (Hubbard et al., 2003). Including people living with dementia in research and wider decision making is fundamental (Innes et al, 2021). This also enhanced validity by using one method to validate another (for example observations confirmed and enhanced participant narratives).

Each data collection method is presented in Figure 10, with how it was organised to capture interactions, stories and experiences between people living with dementia, experiencing delirium, staff and family carers, and how the data collected fed into, and progressed through, the stages of the 4D cycle.

Figure 10: Data Collection Process



Demographic Characteristics

To understand the profile of those involved in the study and describe the sample from each ward or department, demographic information was collected from family members or nursing staff as appropriate. No demographic data was collected for patients observed during the study.

Table 19: Participant demographic data collected staff

Participant number	Gender	Age	Ethnicity	Job role	Length of time in role	Previous dementia training	Personal experience of caring for someone with dementia
1	M	53	White other	RN	37	Tier 1	Y
2	M	59	White British	RN	34	Tier 1	N
3	M	38	Black	Other staff group	5	Tier 1	N
4	M	42	White	Doctor	9	Tier 1	Y
5	F	49	White	HCSW	17	Tier 1 Champions programme	y
6	F	47	White	HCSW	6	Tier 1 Champions programme	y
7	F	28	White other	HCSW	3	Tier 1	y
8	F	60	White	Other staff group	19	Tier 1	N
9	F	37	White other	RN	13	Tier 1	N
10	F	42	White other	RN	11	Tier 1	N

Table 20: Participant demographic data collected-family carer, n=3

Gender	3 females
Age group range	36-81
Ethnicity	White British
Relationship to person caring for living with dementia	Wife=1, Daughter=2

Phase 1 - Setting the scene and establishing relationships

During the first month of the study, I worked in the wards likely to be recruited to the study to establish relationships with the team, answer questions and explain the purpose of the research. While I was not included in the numbers and did not administer medications or attended to tasks such as helping with toileting, I did attend to some aspects of care such as arranging tables, playing music and providing a listening ear. I also answered the telephone and responded to family carers' inquiries (This is presented in Table 20). Developing relationships with individuals and providing reassurance about the study aided familiarisation and noting what looks and feels good for the individuals and participants (Bushe, 2011). This also provided an opportunity for me to meet with family carers during visiting and answer any questions. This provided a good foundation for me to gain insight into the ward culture and team work, and how the language around dementia and delirium was used.

Across all areas it was highlighted how handover processes did not encorporate PCC for patients with dementia and delirium; for example, there was no discussion around the use of "This is Me", no discussion around what helped to alleviate distress, what helped to provide meaningful activicty, how best to communicate with the person and no attention to the person's life story, who was the person inside behind the dementia and delirium. Lofland and Lofland (1984) describe several stances that the researcher can play in research. They discuss the "martian‟ role where the researcher endeavours to view the situation with innocent and fresh eyes. Here the researcher considers their lack of knowledge to be an advantage as it will help them to notice accepted or taken for granted behaviours. While I reflect on and acknowedge I am not completely innocent, or lack understanding of the ward environment and current practices, I specifically chose areas that I spend very little time on. During this period of immersion, I kept some field notes and summarised and have included some key points.

Table 21: Observations identified during immersion work

Ward Type	***Hours spent***	**Observations around delirium and dementia and communication in practice**	***Conversations with family***	***Conversations with staff***
Admissions	*3*	Attended tea round, spoke to patients and family	Discussions around This is Me and prevention of delirium	*Able to identify patients with dementia*
Surgical	*4*	*Witnessed ward round*	Signposted to community support, not aware of what services are availble in community	Staff reported keen to learn more about DSD but time away from the ward is difficult
Surgical	*3.5*	Safety huddle discussed, fall risks, pressure sores, DOLs/MCA and 1-1 care	Discussions about This is Me, family had not been asked beforehand	Staff keen to shown me their ward champions board and identified dementia champions

Acute admissions	*4*	Staff aware of 4AT but not rountinely using this	*Telephone conversation with relative about delirium*	
Medical	*3*		Relatives anxious on the telephone, unable to get through in time. Frustrated about delay in discharge such as medications, conversations and transport	Staff discussed how handover process does not provide enough information

Phase 2 - Discovery Phase-looking for the best of what is happening

This section describes the data collection to discover aspects of dementia and delirium care that worked well as observed in the provision of care and reported by staff, patients and their family carers. During this phase, extensive data collection took place to discover aspects of care that work well on the ward as perceived by staff and family carers.

Observations

Observation is a useful way of understanding and to check whether what people say is important and what they do can be observed in the workplace. They are often the chosen approach in keeping with an interpretive design to qualitative research but are less utilised than the less labour intensive than interview.

(Mulhall, 2003). Mulhall, 2003 describes the following rationale for observations:

1. Provides insights and interactions between dyads and groups.
2. Illustrates the whole picture.

3. Captures context and process.
4. Informs about the influence of the physical environment (Mulhall, 2003).

Observations are widely advocated as a useful method of providing access to the social context, but also to ways of understanding how people act and interact (Holloway et al., 2010, Holloway and Galvin, 2023). Indeed, Strauss and Corbin (1998) see it as qualitative research, *par excellence.* Data from observations provided evidence for naturally occurring events and interactions and complemented evidence from other sources such as interview data (Wye et al., 2014). Observational research can be placed on a continuum ranging from participant observation at one end to coding of number, types and frequencies of behaviour at the other. (Astell et al., 2009; Costello, 2001; Perrin, 1997; Norman, 2006; Wind, 2008).

During the non-participant observation phase, the role assumed was that of an observer as participant—present on the wards, identifiable by everyday attire and a name badge, yet not actively engaged in the activities being observed. (Gerrish & Lacey, 2010; Holloway & Wheeler, 2013, 2023).

The initial aim to record events in patient areas without influencing events, interactions and care processes (Handley et al., 2020), and to understand how care is organised for people with or at risk of DSD and inform subsequent interviews on what works well. Observation was first to understand the ward environment and then to focus on the interactions between staff, family carers and patients with or at risk of DSD.

Data collection focused on the observation of patients with dementia in the ward setting and the staff, patient and family interactions and events that occur. It documented the context of care, such as the environment, staff mix and ward routines, and how staff actions could be linked to patient and family carer responses. The focus was on what works well. This included examples of effective communication, anticipatory care or interventions that minimised the person with dementia distress. By recording and recognising the detail of how staff interact, initiate conversations, who spent most time with people with DSD and affected their responses provided data that could inform accounts of what makes a difference to the patient and their family. Observations also noted how family members engaged with care. Text box 2 summarises the purposes of observation in this study. Field notes were written, where possible, during and directly after observations and expanded on by the researcher at the earliest opportunity following data collection.

Table 22: Rationale for non-participants

1. Understand what is working well in dementia and delirium care, identify examples of good relational care which may not have been considered or discussed at interview.
2. Help people living with dementia in the hospital feel more comfortable with me and to gain their trust (Boyle, 2014, Dewing, 2008, McKillop and Wilkinson, 2004, Tanner, 2012).
3. Identify myself to family carers, respond to any questions they may have around the non-participant phase or questions about the interview process.
4. Familiarise myself with the ward routine and the teams working there, ensuring they understand the rational and purpose of my research and I do not cause additional work for them in terms of handover and the consent process.
5. Notice the key everyday decisions staff caring for patients with DSD make and how this is communicated with their team, other professionals and family carers in hospital.
6. Begin to understand how nursing staff recognise when a person living with dementia may have delirium, how they may respond to unmet needs/distressed reactions, and the skills, resources or personal characteristics they use to facilitate that.
7. Prepare for the process consent method used for interviews and with family carers who may have communication difficulties who had limited or fluctuating capacity (Dewing, 2007, Dewing, 2008).
8. Familiarise myself with how ward environments and their participants (staff)' present under 'normal' everyday circumstances.
9. Familiarise myself with the environment, consider how this may support, enhance or cause disruption and increased confusion to a person with DSD.
10. Identify contextual factors associated with each ward; their culture and practice, routines and how legal and policy frameworks (e.g. The MCA 2005) are reconciled with and ethical drivers and time and resource allocation. I used semi-structured non-participant observations to identify examples of good practice in delirium and dementia care.

Due to the embedded and invisible nature of many nursing interventions and practice, the observations were descriptive and detailed accounts of what was happening. Staff might not have been consciously aware of how particular actions and responses are supportive interventions when delivering care for patients and their families with DSD and may therefore be unable to recount these in interviews (Leininger 1985).

Observation Procedures

Five periods of working within ward areas that were less familiar to myself totalling 17.5 hours (Table 20), to immerse myself in the setting, were completed. During this time, I listened into handover, I got to know the teams, I assisted with refreshments and spoke to staff and relatives, if approached. This was not included within my own working hours.

Observations involving healthcare professionals, patients and family carers caring for patients with DSD took place at different time points. To reflect the busy and quiet times, and times when patients are known to experience higher levels of patient distress and delirium related falls, for example between 7-8am and 8-9pm during staff handover periods. Twelve periods of non-participant observation over different time points, (n=36), observing 74 patients with DSD were completed.

Using unstructured, non-participant observations to identify examples of good practice when caring for patients with DSD I was able to gather examples of relational care between staff, patients with DSD and their family carers. Noting any interactions and resulting behaviours that could be explored within the interviews. I discussed the use of Dementia Care Mapping (DCM) (Kitwood and Bredin, 1992, 1997) in the design phase with my supervisors. I had previous experience using this tool when undertaking the Quality Mark (RCP. DCM), as an observational tool records ‘positive events’ and ‘personal detractors’ where staff interact positively with people living with dementia, or negatively, for example using mockery or infantilisation. However, DCM provokes anxiety in some staff (Brooker et al., 1998) and a burden for others (Griffiths et al., 2021) which contradicts the philosophy of the AI methodology. After discussion it was felt this may be too restrictive and may prevent me capturing all the activity.

I considered other tools, such as the Newcastle Model, a framework to understand behaviour that challenges (Appendix 13), but it became apparent based on my experience of Dementia Care Mapping and reviews of other tools, that they would limit the accurate recording of every interaction between staff, patients with DSD and family carers. They would also limit the observation of the environment and how this impacted on people with DSD. I made field notes overtly, in real time, during the observation periods to help me capture the detail and richness of the relationships and interactions between patients and their staff and family carers. These notes on how interactions between staff, patients and family carers were created, recognised, and were recorded in addition to any resulting outcomes of the decisions. I recognise that my field notes were unavoidably subject to observer bias (Fitzpatrick and Boulton, 1994) and this was addressed in supervision and through maintenance of reflective diaries (see Appendix 15).

Interviews/story generation with staff

To understand the nature and different ways relationship-centred care was enacted, interviews encouraged staff to recount their experiences. Stories were a valuable way of revealing the meaning and ambiguity of everyday situations (Patricia Benner et al., 2009; Sandelowski, 1991 and Adma & Widdershoven, 2005). During the discovery phase of this study, interviews with staff supporting a person with DSD used reflective questions, such as:

Think of an episode of caring for a patient with DSD

1. What helped you recognise the person may have or was at risk of DSD?
2. What approaches worked well in this scenario and why?
3. Reflecting on this example, what would you do differently next time?

Affected by staff availability, interviews were audio recorded and carried out in a room away from the wards.

Building on information gained from the periods of observation, the interviews focused on what staff recognised from the findings as examples of good practices, and if they had additional accounts or alternative interpretations of what had been observed.

Inviting staff to share their experience of good work and responses to the observation findings were a source of consciousness raising (Dewar et al., 2007, Dewar et al., 2010).

Individual interviews/stories with family carers (and patient if requested)

Interviews with family carers supporting a person with DSD adopted a story telling approach using emotional touchpoints.

Emotional Touchpoints

The NHS Institute for Innovation and Improvement has developed several tools that enable practitioners on the ground to develop more effective services in partnership with patients (Dewar et al., 2009). Their EBD approach (experience-based design) captures the experience of the care journey for all those involved, in addition to the emotional journey people experience when they meet you. One of these methods is emotional touchpoints.

Emotional touchpoints in research refer to specific moments or interactions that evoke strong emotional responses from participants. These touchpoints can be significant events or small acts that leave a lasting impact on individuals. They are often used in qualitative research to understand people's experiences, feelings, and memories related to a particular service or interaction.

For example, in healthcare research, emotional touchpoints might include moments like receiving a diagnosis, interacting with a healthcare provider, or experiencing a particular treatment. By identifying and exploring these touchpoints, researchers can gain deeper insights into the emotional and cognitive aspects of participants' experiences, which can inform improvements in service delivery and patient care.

Capturing the voices of patients has been approached in a variety of ways, this may include surveys, stakeholder events, interviews, focus groups and in specific to dementia, National Audits. These approaches tend to concentrate on attitudes or statements about what is good or bad rather than specifically understanding the story or the experience for the individual. What is highlighted in published studies is the importance of experiential knowledge from patients to help develop services (Fudge et al., 2008).

The patient story is incredibly valuable in healthcare as it vividly captures the multilayered texture and complexity of experiences in hospitals. These narratives reveal the intensity and human significance of the patient's journey, offering unique insights into the relationship between the care process and the patient's world.

Patient stories have the unique power to engage and move listeners, helping healthcare professionals understand the emotional and psychological dimensions of patient care. These narratives provide invaluable insights that can inform more empathetic, patient-centred approaches to care, ultimately improving the overall patient experience. Noval et al., (2020) discuss, people often share information in the form of stories, using conceptual resources and artefacts. Stories are useful for understanding individual experiences of illness (Gidman, 2013, Kleinman, 1988), and for discovering these experiences within a larger meta narrative of specific communities (Novak et al., 2020).

Goodrich and Cornwell (2008, pg.7) emphasise the importance of the patient story as it communicates 'vividly the multilayered texture and complexity of experience in hospital, its intensity and human significance.... they have a unique power to engage and move listeners and provide invaluable insights into the relationship between the care process and the patient's world'. Ways of eliciting stories in clinical practice have been designed and include the use of talking mats and discovery interviews. Both methods use a series of prompts to help the storyteller to describe their experience. The talking mats method uses a visual framework and has been developed with people with learning disabilities and frail older people (Murphy et al., 2005).

The NHS Institute for Innovation and Improvement is developing several tools that enable practitioners on the ground to develop more effective services in partnership with patients. One of the methods they highlighted is the use of emotional touchpoints. The method focuses on emotion by asking patients and their families to think about key points in the patient journey, and to select from a range of emotional words those that best describes how they felt about an experience. The method incorporates key elements of the talking mats, and the discovery interview approaches as discussed above. The method thus helps the interviewer and interviewee to directly focus on the emotion related to the different points (touchpoints) in the patient experience. The focus on emotion is seen as crucial to the development of effective and meaningful relationships between patients and professionals (Freshwater and Stickley, 2004). This is further supported by others who believe that the ability to recognise the emotional world of another is a pre-requisite skill for any caring profession (Cadman and Brewer, 2001).

Dewar et al., (2010), in a study exploring carer outcomes in relation to dementia, identified pre-selected 3 core touchpoints: caring together, my life and the future. They concluded that the use of emotional touchpoints builds upon what is working well, enabling a strengths-based approach with carers (Dewar, 2012) and opens dialog (Dewar et al., 2010, Macbride et al., 2020). The Alzheimer's Society describe emotional touchpoints as an interview method you can use with people with dementia. They are also useful to find out what an experience feels like to a service user, their family and friends, identifying small actions that can make a big difference. The risk to using this tool for some people with dementia is that too much choice could be overwhelming. Based on Professor Belinda Dewar's guidance on using emotional touchpoints (Emotional Touchpoints in Action, My Home Life Scotland 6 - University of the West of Scotland on Vimeo). I initially encouraged participants to choose 2-3 points/topics of conversation to focus on, this included:

- Visiting my family member
- Talking to staff
- Discharge Planning
- Being involved with decisions
- Talking to staff
- Care of my family member
- The future
- The environment

Then using a list of emotional words, positive and negative, (examples below), to sum up how they felt about the topic:

Positive - satisfied, safe, cared for

Negative - sad, unhappy, frustrated

I asked participants to choose some words that reflected how they felt about the chosen topic, for example, one participant chose:

Talking to staff - frustrated, unhappy, angry

Emotional touchpoints within the interviews in this study provided a method of tapping into the experience of receiving care in the hospital setting (Dewar et al., 2010). Dewar described interviews focused on emotional responses to events by asking the patients and family to consider key points in their experience (touchpoints), selecting from a range of emotional words, e.g. happy, angry, sad and isolated, used alongside the photos that best describe how they felt about the experience (Bate & Robert, 2007, 2009). Examples of touchpoints were family member's admission to hospital, going for tests, talking to nurses, mealtimes, disruptions to usual routine, noise level and family contact (Dewar et al., 2010).

Interviews were in a private room on the ward or at the participant's home. The touchpoint prompts were placed on a table and the family carer/staff member selected those they would like to talk about.

All participants were offered the opportunity to review the transcript/ notes of their interviews.

Individual interviews/stories with patients with dementia who can consent

Interviews with patients with DSD were intended to also take a story telling approach using emotional touchpoints. However, no patient was available or had the capacity to take part in the interview.

Phase 3 - Dream Phase - exploring the ideal approach to dementia/delirium care

Three main activities took place during this phase:

- Interviews using a story telling approach and emotional touchpoints.
- Beliefs and values clarification exercises to explore the "dream" or "ideal" with staff.
- Comparing what was observed during non-participant observation.

Beliefs and values exploration to create the ideal

The Dream phase explored the themes that emerged in the discovery phase and used them to encourage participants to think beyond what was ordinarily possible through identifying common aspirations and goals (Bushe, 2011), developing further relationships and providing an opportunity for participants to share their dream ideas, however this also enabled me to gather hopes, dream and aspirations for the future.

Using a story telling approach gathered those examples of when staff had provided care that had really made a difference but often felt unnoticed or unheard, and for family carers it provided an opportunity for them to feel valued and to be encouraged that they were doing well.

Following this research future plans will include meeting with staff in small group, such as the Dementia and Delirium Champions and the volunteers to discuss the findings and explore beliefs, values and philosophy that currently informs the care for people with dementia and delirium. Staff will be encouraged to discuss what they value in their work, what helped them to care in a way they wanted to, and to imagine what care they would like to receive if they were a patient or relative.

By understanding their beliefs and values, a vision for their ideal caring approach to patients with DSD can be developed. It will highlight if their ideal matches their reality and, if not, what changes they would like to see happen to the service they provide. Through the process of feedback and exploring beliefs and values, an ideal vision/approach to dementia and delirium care that will be owned by staff can grow and develop.

Reflexivity

Part of the research process is reflecting on how a researcher's views, attributes and experiences impact on the research (Madill et al., 2000). A reflexive journal and post-interview field notes to record thoughts and questions of the interview experience, decisions that were made, challenges that were addressed and how key themes were identified during the analysis supported that process (Appendix 15). Noting down analytical decisions that are made early in the research process supports transparency and trustworthiness and a decision trail when writing up the findings (Frost, 2016).

A summary of the data collection through the phases of the AI approach is seen in the table below.

Table 23: Data Collection

Phase	Activity/Data Generation
Phase 1 - Setting the scene and establishing relationships	• Field work including informal observation and informal discussions • Informal interviews with staff to explore their views about the study • Presenting the study at nursing forums • Presenting the study at the Trust Research and Development committee
Phase 2 - Discovery-what is working well?	• Non- participant observations • Staff and volunteer stories • Patient stories • Family stories • Field work including informal observation and informal discussions
Phase 3 - Dream/Ideal- What would the ideal supportive environment be?	• Reflecting on non-participant observations • Interviews with staff • Interviews with family carers • Field work including non-participant observations • Identify specific actions that staff are keen to take forward for future work

Data Analysis

The analysis of the data was an iterative process, and interpretations of early findings were further explored in subsequent interviews.

Transparency in AI is crucial for fostering trust, engagement, and effective collaboration, so that many contributions to theories can be evidenced. Some keyways that transparency can be applied in AI are:

- Open communication: ensuring that the process, goals and outcomes of the inquiry are communicated to all stakeholders as this builds trust.
- Inclusive participation: to involve a diverse range of voices in the process.

- Reflective practices: encouraging continuous reflection and feedback, transparency in reflecting on what is working well and what could be improved fosters a culture of learning.

The way that the data were generated (and analysed) with, and by the participants themselves, influenced the analytic process. Participants came with examples of Dream ideas, some of which in their individual environments had begun to develop into design. Therefore, some of the interview provided an opportunity to reflect and articulate through discussion, debate and exploration of why something was seen to work well (an example of this was a HCSW speaking about having the confidence as a Dementia Champion to support other staff). This is a usual approach in AI where participants' interpretations feed into the data synthesis and analysis (see for example, Clouder and King, 2015 and Whitney and Trosten-Bloom, 2010).

Seventy-four patients were observed through non-participant observations over 12 different time periods totalling approximately 16 hours. The write up of these observations was completed, transcribed and analysed by me. I transcribed all 13 interviews. Transcription is a necessary step in the research process; it helps researchers know their data. Transcription is an important familiarisation process and contributes to the first level of analysis (Woolf and Silver, 2017).

Field notes, non-participant observation data and interview transcripts were coded initially under descriptive categories using NVivo 10 software.

The overall analysis approach drew on the principles of Immersion/Crystallization described by Borkan (1999). Unlike the structured approach of thematic analysis, which involves coding data according to pre-defined themes, this approach allows themes to emerge more organically from deep engagement with the data (What is immersion/crystallization method? - Kaspar Roost (roostkaspar.com). This is a style of data appropriate for exploratory research where knowledge in the area is limited, and research is participatory (Kilbride, 2007).

The process involved a number of stages: initial description of the data, crystallising the core messages, the process of temporarily suspending, the process of examining or reading the data (immersion) in order to reflect on the analysis experience, and attempt to identify and articulate patterns or themes in the data extracts, considering theses in relation to all other data, reflecting these back to participants, and creative synthesis (how the data is emerging from the participant's experiences and the researchers personal knowledge of the phenomenon, taking an artistic representation of the findings and corroboration of themes).

This approach particularly worked well for the following reasons:

It was intuitive and flexible: It allowed for a more fluid and inductive process rather than rigid coding schemes. It was emotionally and cognitively engaging by connecting with the data on a more personal level. It provided a framework to consider the complexity of social and cultural issues and relational working and how this shaped the data and its interpretation. Finally, it helped me to ensure the concept of partial truths and understanding that analysis is one viewpoint among many, aligning well with relational constructionist views of knowledge.

How this process was used in this study is provided in Table 22.

Table 24: The Process of Immersion/Crystallisation

Elements of immersion/crystallisation process	**How elements will be carried out**
Initial engagement with the topic/reflexivity	Recognising and reflecting on hunches and prior knowledge and experience debated with other senior nurses and documented in reflective diary (Appendix 15)
Describing (collaborative activity with wider team)	Initial introduction to the field and data generation. Reflecting on current themes to form the framework for initial data analysis. Derived from team members, initial orientation and early data (mainly informal observation)
Crystallisation during data generation	This will begin as soon as the first question is asked. I will consider consciously what strikes me about the data, are there "lightbulb" moments, what stands out, what is at the heart of what people are saying, are there any surprises? What elicits emotions and why is this the case. Noticing the mundane, noticing the exceptions.

	Generating questions for further inquiry and analysis.
Immersion and illumination of emergent insights from collected data	Systematic review of all data. Read through again each piece of data and begin to develop sub-themes from the key messages from each piece of data. Organise sub-themes around main themes.
Presentation of sub-themes to research supervisors	Present sub-themes to research supervisors. Read through all data, discuss any significant findings/debates of themes with research supervisors.
Explication and creative synthesis	Re-examine initial data analysis and refine areas of dissonance Paying particular attention to themes and sub themes. Once all data is assigned sub-themes and situated under different key themes these will be re-read to check that data entry continues to reflect the overall sub-theme and theme.
Corroboration/legitimation and consideration of alternative interpretations	Pose alternative questions on the themes and sub-themes to force consideration of alternative responses. Search for alterative responses in the literature and with colleagues and participants. Review reflective diary to enable more thorough understanding of my interpretations (Appendix 15)
Representing the account/reporting	Organise textual accounts for dissemination. Provide detailed description of both process and outcome of analysis.

Example of an aspect of data moving from description to interpretation

When describing the experience of her husband being hospitalised with delirium, one participant said:

“*They came to do the mental capacity act, that in itself is wrong because this man is not medically well, it’s not the mental state you need to sort out, its what’s causing it, I should have challenged them, but I was just traumatised with it, but I realise now what was happening to him, his body was totally unbalanced by the delirium”.*

Using NVivo and the following nodes and codes were developed:

Delirium - delirium presentation, distressed reactions, pharmacological versus non-pharmacological interventions, physical or mental health

Education and knowledge - cultural perspectives, family experience of delirium, staff education, staff understanding of delirium

Environment - Cinderella service, COVID-19, physical environment, investment into dementia services, visiting, ward activity

Fundamentals of care - better delirium care, deconditioning, dissonance, leadership culture, moral distress, patient experience, responding to bad practice, staff distress

Relational care - communication, empathy, going the extra mile, philosophy of care, spiritual care, staff and family carer relationship

Supportive Interventions - dementia champions, Namaste, Pets as Therapy, musical activity

Workforce - specialist support, staffing, volunteers

(The exert from interviews on page 119 is broken down into nodes, using a colour as highlighted).

Patient and public involvement

The voice of people living with dementia is not often sought to inform research about issues directly affecting them. The challenge for researchers is to find suitable ways to involve people with dementia to learn about their experience of living with the condition and the care they receive.

Increasing PPI in research is an established policy in the UK (Department of Health, 2006).

The National Institute for Health Research states that public involvement is “research being carried out with or by members of the public rather than to, about or for them”

(National Institute for Health & Research, 2019). The level of public involvement can vary considerably, from basic participation in research studies to user-led research (Wilson et al., 2018). A shared understanding between the researcher and participants will mean that trust should be more easily established (Hodge et al., 2020).

Building celebrative relationships was important to me as an individual and an important part of this study. The importance of stakeholder engagement and collaborative working is discussed by Marrow et al., (2024), described as essential in exploring the most important issues for people living with dementia and their family carers in hospital. Initial stakeholder consultation with healthcare professionals from the research site and community dementia and carer organisations, and a second event inviting family carers, highlighted a range of patient care issues related to the fundamentals of care for people living with dementia in the acute hospital setting. Examples provided include, “staff not knowing the patient”, visiting, understanding how to support distressed behaviour and practical issues such as car parking.

The Information leaflets, consent forms and other research documentation were shared with the patient panel based at the Trust where the research was carried out, the Harlow Dementia Action Alliance and with people living with dementia and their family carers who attended Dementia Friendly coffee mornings. Collaboration strengthened relationships with stakeholders, people living with dementia and their family member/carer, opportunities influenced my approach to the study, my methodology and the interview questions, and I continued to foster these relationships throughout the duration of the research and was ongoing.

They were asked for their thoughts around the research approach and the use of photos, patients and their family carers in the study. These consultations included three people living with dementia who reviewed the research information. They highlighted areas that were particularly well described, and those that needed further explanation. For example, they felt the images were useful and made sense, they suggested the font could be a different colour to make it more appealing but, overall, they understood the information. What was really pleasing was their enthusiasm for the research and the commitment to helping others.

Patient engagement in research related to dementia was explored in a scoping review Bethell et al., 2018. The review addressed the following questions with respect to dementia related research (Arksey & O'Malley, 2005; Levac et al., 2010) (Table 23).

Table 25: Scoping studies: Towards a methodological framework: Arksey and O'Malley, 2005

Research Questions

1. What approaches have been used to engage persons with dementia and their care partners in different phases of research, including preparation, execution and translation?
2. What are the reported barriers to engaging persons with dementia and their care partners in research?
3. What are the reported enablers to engaging persons with dementia and their care partners in research?
4. How has the impact of engaging persons with dementia and their care partners in research been evaluated?

Ensuring the voices of people living with dementia are heard, listened to and fundamental to high quality dementia care is what drives me forward in my professional role. While this study did not get the opportunity to hear the voice of someone with dementia spoken in interview, non-participant observation enabled that opportunity. My interest in involving people living with dementia in research is ongoing and I have joined the EMPOWER Network, a network of people who want to join to make things fair and equal for everyone with dementia needing support. The network is funded by the Alzheimer's Society in partnership with the Economic and Social Research Council (ESRC) and National Institute for Health and Care Research (NIHR). The network's aim is:

- To work together and provide creative ways to make a positive difference in dementia care.
- To hear the voice of people from marginalised, vulnerable and underserved groups about what matters to them.
- To find new ways to do research that mean more people with dementia can take part.

The impact of PPI on people living with dementia, the public, dementia researchers and the research process in the European Union was explored in a scoping review, Miah et al., (2019). Only three studies formally evaluated using methods such as questionnaires, semi-structured interviews and focus groups the impact of PPI in dementia research (Littlechild et al., 2015, Stevenson and Taylor, 2017 and Morgan et al., 2018). PPI is suggested to increase the cost effectiveness of research by suggesting research outputs are appropriate to the patient group of interest (National Institute for Health Research, 2019). I believe the groundwork in preparation for this study strengthened the output.

Credibility and Trustworthiness

Credibility and trustworthiness are crucial in dementia care research due to the vulnerability of participants and the ethical complexities involved. Validity, reliability and generalisability of results are quality markers and evidence of research rigour (Johnson, 1997, Silverman, 2013).

The multi-method approach to data collection enabled me to validate findings about what I thought I already knew and, added to by the consistent nature of the interviews, enabled me to check understanding with the participants (Clouder and King, 2015, Reed, 2006, Trajkovski et al., 2013).

Reliability in qualitative research is a crucial aspect that ensures the consistency and trustworthiness of the research findings. Key points that were considered:

- Dependability: I made real time notes of observations, digitally recorded interviews and completed field notes. The recordings were transcribed verbatim to minimise my interpretation in reporting the data (Seale, 1999, Silverman, 2013), to enhance dependability.

- Credibility: This refers to the confidence in the truth of the findings. I used non-participant observation over many different time points to improve credibility.
- Confirmability: Ensuring that the findings are shaped by the respondents and not by researcher bias, motivation, or interest. Reflexivity was a useful technique, in discussion with peers, the Research Department and my academic supervisors.
- Triangulation: Multiple methods used included setting the scene and establishing relationships, non-participant observation and interview. This helped with cross checking and enhanced reliability of data, helping to ensure that the findings were not from a single source.

Chapter Summary

This chapter began by introducing the paradigm of relational constructionism as the underlying philosophy for AI. This paradigm highlights that research is done **with** and for people, the researcher is part of the process, and that knowledge is created through practices, experiences and interactions in the unique context of the acute hospital setting, in that it involves participants in both the change and research processes and facilitates the generation of practical and theoretical knowledge. AI was proposed as the most appropriate research approach to explore delirium superimposed on dementia (DSD) and relationship centred care.

This chapter described the data generation activities during different phases of AI (Discover, Dream, and working towards Design) in the Phase 2 study design. I have identified how consent processes were implemented to overcome ethical challenges. It reflects on the importance of these methodological details to both the study aims and their consistency within the paradigm of relational constructionism. Finally, details are given of methods to enhance the quality of the research to help the reader judge the quality of the findings in the following chapters.

Chapter 4 - Discovery Phase

Introduction

This chapter, and the chapter that follows, present the findings and outcomes of the Appreciative Inquiry (AI) process.

This chapter includes.

- a description of non-participant observation
- purpose of observation
- a description of the study setting and participants.
- using non-participant observation to identify what works well in dementia and delirium care
- participant characteristics

Some data are presented in tables, with example excerpts from observation field notes and interview transcriptions aiming to represent the voices of the participants. Findings from the discovery and dream stage of the 4D cycle are presented in Chapter 5.

Observations

Non-participant observation plays a vital role in dementia research, especially when aiming to understand lived experiences in care settings without disrupting them. It captures real time interactions; it allows researchers to observe how people living with dementia interact with their environment and their relationships with staff and peers without the researcher involvement influencing behaviour. Observation helps researchers notice gestures, facial expressions, body language and other non-verbal cues which may reveal emotional states, particularly important in dementia care research for those people living with advance dementia who may not have a voice to express their needs. In realist observations (Handley et al, 2019), non-participant observations help to identify the mechanisms that drive care practices, for example staff decision making driving person centred care. Lastly observational data can reform and refine theoretical frameworks by linking observed behaviours to contextual factors and outcomes particularly in challenging environments such as hospitals.

The purpose of the observation was to provide an in-depth understanding of the context and day to day practice. I used observations to step outside of my clinician role to observe how people care for patients with DSD, and possible lines of enquiry around improvement or where it was unclear why people made the choices they did. My role as observer as non-participant was not to engage with staff during the period of observation unless there was a specific clinical or patient harm concern. The non-participant observations provided me with insights in preparation for the interviews. Using an appreciative inquiry framework meant the focus was on examples of what works well. The assumption was that participants (staff) may not be aware or recollect/recognise which of their actions led to positive patient and family responses, especially if certain behaviours were how they always approached care.

There were a few isolated incidents where I was approached to intervene, as I am known to the research site. This happened during a period observing a COVID-19 isolation bay when a patient rapidly declined, and no staff members were around and, on another occasion, when two patients with DSD potentially could have harmed each other. There were also other occasions where I found not acknowledging a patient’s distress too upsetting to overlook.

Observations were conducted to capture a range of activity during the day between 06:00-21:00, for example on waking, during morning personal care, during staff changeover of shifts/receiving handover during the morning period and including lunchtime and evening meals, ward descriptions are described in (Table 24). If participants slept all day, observations were carried out in the evenings and into the night. This ensured the collection of data on interactions that reflected the patient’s experience linked to the events and routines of the ward. It also allowed observations of participants’ sleep-wake cycle and what facilitated or disturbed it.

Table 26: Descriptions of wards /specialities/periods of observations

Ward Number	Speciality	Periods of Observation	Time of Observation	Number of male/female observed with DSD	Number of Beds	Ward Consultants	Dementia Delirium Champions
One	COE	Two	18:00-19:00	6f/2m	28	Two	Seven
			06:00-07:00	5f/2m	28	Two	Three
Two	COE	One	15:45-17:15	4f/4m	28	One	Three
Three	Medical	Two	18:45-20:20	6f/3m	28	One	Three
			16:30-20:15	5f/3m	28	One	Three
Four	COE	Two	07:00-08:30	5f/2m	28	One	Two
			17:30-19:10	4f/3m	28	One	Two
Five	Frailty	Two	16:45-18:15	3m/5f	17	Two	Two
			17:00-19:00	4f/1m	17	Two	Two
Six	Surgical	One	18:30-19:30	2m/2f	28	Visiting	Two
Seven	Medical	One	15:45-17:15	5m	32	Two	Two
Eight	Surgical	One	07:00-09:00	3f/2m	28	Visiting	Four

COE-Care of the elderly, Visiting=Ward covered by various consultants' dependant on speciality needed

F=Female, M=Male

The observations were all based in one hospital and reflected the layout and environment consistent with the hospitals of this era (1950s). However, how the nurses positioned themselves in the ward, how the wards were maintained and decorated, were observed to have an impact on the environment, noise levels and if there was evidence that the needs of people living with dementia had been considered.

Ward Descriptors

Wards one, two, three, four, six and ten have 28 beds. Wards one, two and four are Care of the Elderly wards. On these wards, there is a similar layout: this consists of two bays of four males, four side rooms and a 16 bedded female or male end divided into four sections of four. For every ward, a side room is situated next to the nurse station/desk area. There is a quiet room for relatives on wards one and two; on ward four, the quiet room is multi-purpose and used by staff taking their breaks. On ward one there is a reminiscence room used at times for Namaste with equipment such as a sensory trolley, a Reminiscence Interactive Therapy Activity (RITA), and some other equipment such as puzzles and books. Bays can be interchangeable and are used flexibly to meet the needs of the hospital for patient accommodation. There are no nurses' stations in the patient areas. When patients require close observation, and there is no one available for constant observation, staff are observed to take their computer on wheels and work sitting by the patient's bed. In one ward, which has previously been a day room, it is now used as a multi-disciplinary meeting room with desks and computers, used by many different professionals such as Doctors, Nurses and Allied Health Professionals (AHP).

Wards one and two were refurbished in 2021, with visible attempts to ensure the environment was dementia friendly. The doorways have been defined in a different colour to the walls, with some dementia friendly signage, for example a coloured wall mural, a dementia information board and way finding signage such as toilet signs with the word and picture. The ward is brightly lit, and, other than one mural, the walls are blank with notices for staff and visitors. It is modern and clean, but feels clinical, with good natural lighting and is observed to be quieter with a calm atmosphere, when compared to the other wards observed. Some patients have a bed side television and "forget-me-not" poster on their board (visual indicator used in UK hospitals to highlight patients with dementia/cognitive problems).

Ward five is a purpose-built frailty unit, adjacent to the Accident and Emergency Department. The unit is new, has a bright and open feel, and has a nurse's station in a central area with a sign "Welcome to the unit". There is evidence of interventions to help orient patients to time and place. Each bed area has wall art above the bed with the number of the bed space, a picture of a flower/nature design all in the same colour. There is access to five Reminiscence Interactive Therapy Activity, Television (RITA TV'S), they have a projector displaying the daily news. They have dementia friendly clocks, a calendar with the date/time and pictures of the weather. There are no windows in this unit and therefore no natural light. There is lightening in the ceiling to depict the sky.

Ward three is a general medical ward with a speciality in Endocrine. Ward seven is a medical ward with a speciality in respiratory. Ward three had a light touch refurbishment in 2021 and is well lit and bright. Ward seven, in contrast, has a dated appearance with dark flooring and a more closed in design, making its appearance quite a dark environment, with some natural lightening in only a few areas. There is a central nurse's station that only has a sightline of four of the thirty-two patient bays.

Ward 6 is a surgical ward. This ward has plastic screens between the bed spaces in the 16 bedded end of the ward for infection control purposes. This ward also has sliding doors across each 4 bedded area within the 16 bedded end. The doors are opened by touch and create a way of isolating patients who may be infectious, but on this period of observation there were no infectious cases. These areas however cause a reduction in noise, therefore if a patient is calling out, they may not be easily heard.

Table 27: Themes derived from non-participant observations

Primary Theme	**Sub-Theme 1**	**Sub Theme 2**	**Sub Theme 3**
Organisation of Care	Ward level	Trust level	Clinical need
Recognising and responding to distress/expressed needs	Agitation	Staff response to agitation	Type of staff caring for people with agitation
Presentation of delirium	Hyperactive	Hypoactive	Mixed
Environment	Noise	Activity	Visiting
Supportive Interventions involving activity's	Doll Therapy	Music Therapy	Building relationships
Type of staff Intervention	Reassurance	Instrumental	Proactive
Close Observation	1-1	Enhanced Care	Cohort
Communication	Staff-Patient	Staff-Family Carer	Family Carer-Patient

Using non-participant observation to identify what works well in dementia and delirium care.

In the following section, examples are provided of how the data from non-participant observations contributed to refining the interview content and linked prompts to explore into what is working well and using emotional touchpoints.

Seventy-four patients were observed with delirium superimposed on dementia over 11 different time periods of observation and across 7 different ward specialities.

Observations lasted between 60 minutes-150 minutes depending on the number of patients who met study criteria for observation. Delirium superimposed on dementia (DSD) was recorded on the staff electronic handover database which is accessible by all trust staff that work clinically and need access, within the frailty proforma and the medical records. These patients presented with a wide range of symptoms. Those that appeared to cause more distress were hallucinations, both visual and auditory, and altered perception.

Of the 74 people observed with DSD, seventeen appeared to hallucinate, this was characterised by talking to people and seeing objects that were not there and picking up on environmental noises and interpreting them differently. Twenty-three were calling out and looked distressed. Those with more persistent calls for help or distress appeared to be distressed reactions in response to expressed needs not being met (e.g. crying and anxiety and the need to go to the toilet). Eleven had documented reports of hypoactive delirium in their care notes and this was often described by staff as being drowsy; they were concerned they had not been eating and drinking or taking their medication. Participants' characteristics are included in Table 26.

Table 28: Participants' characteristics

Ward Number Observation period	Gender	Age Range	Ethnicity	English as first Language	Type of delirium if known	Number of patients who were not recognised as having delirium	Beds
One Observation period 1	6f/2m	63-91	8 WB 1 Black I Indian	6	5 Hyperactive 2 Hypoactive 1 Mixed	20	28
One Observation Period 2	5f/3m	59-81	1 Indian 1 Chinese 6 WB	6		20	28
Two	4f/4m	68-93	2 Black 1 Indian 5 WB	5	4 Hypoactive 2 Hyperactive	20	28
Three	6f/3m	69-97	8 WB 1 Italian	8	1 Mixed	19	28

					3 Hyperactive 3 Hypoactive		
Four Observation One	5m/2f	66-96	1 Indian 1 Black 5 WB	5	4 Hypoactive	21	28
Four Observation Two	4m/3f	58-89	1 Black 1 Turkish 5 WB	5	4 Hypoactive 2 Mixed 1 Hyperactive	9	17
Five Observation One	3m/5f	56-101	2 Indian 6 WB	6	4 Hyperactive 2 Hypoactive 1 Mixed	9	17
Five Observation Two	1m/4f	62-86	1 Indian 4 WB	4	3 Hyperactive 2 Mixed	12	
Six	2m/2f	79-86	1 WB 1 Polish 1 Indian	1	1 Mixed 1 Hyperactive	20	28
Seven	5m	54-81	1 Indian 4 WB	4	3 Mixed 2 Hypoactive	27	32
Eight	2m/3f	69-82	4 WB 1IBlack	5	2 Mixed 2 Hypoactive	23	28

Organisation of Care

The allocation of patients to specific wards was done through the clinic site team/bed manager. Staff, three times daily update a system called safe care. The Safer nursing care tool (SNCT) is a NICE endorsed evidenced-based tool, to enable a safe and consistent approach to the allocation of staff, recording of staff moves/sickness, and the clinical acuity and essential care of the patients. Consideration to the allocation of patients with DSD to wards is based upon this and the expertise of the ward area.

The organisation of care was led by the nurse in charge/ward manager. If staff felt the stimuli on the ward was adding to a patient's distress, and a patient required a side room due to DSD, staff were observed to seek permission from the bed manager, often via the matron. Staff demonstrated they were responsive to the needs of patients with DSD during five interactions/conversations during the non-participant observations. However, despite staff being observed to provide a clear rationale for the need for a side room, it was often not facilitated. Staff commented that this may be due to a lack of understanding of what triggers distress in people with DSD and the level of demand for beds, plus the system capacity to accommodate these types of requests.

In wards where patients had been identified as requiring constant observation, staff providing this consisted of Health Care Support Workers, agency staff (nursing (Registered Mental Nurse, RMN or unequal), Registered Nurses (RN), Enhanced Care Health Care Support workers, who are line managed by the Falls lead matron and allocated by the site team to wards needing additional support. There were times this may also be provided by volunteers. Where this was not in place they were either allocated to the patient bay, or for some patients no staff allocation was in place.

Twelve patients were observed to be in receipt of constant observation across eight wards. On eight wards responsibilities for monitoring people identified with DSD, and at risk, were shared between staff. The following summarises how this was organised across the different ward settings:

- On ward 1, period of observation 1, 3 female patients were receiving support from qualified staff in a cohort area, 2 male patients were receiving constant observation from one enhanced care nurse.
- On ward 2, 1 male patient was being constantly supervised by an RMN, alongside 3 other male patients in the ward, the seven female patients were being supported by Registered Nurses.
- On ward 4, one enhanced care nurse was allocated to a female who was walking with purpose, 1 RMN allocated to the males, but no cover for break.
- On ward 5, during both periods of observation, all unit staff took a responsibility to provide supervision, i.e. therapy staff, ward clerk, junior nursing staff and student nurse.
- On wards 6 and 8, there appeared to be no additional staff support. On ward 7, patients were cohorted in 2 days nearer the nurse’s station, 1 patient had a RMN for support.

Over five wards, twenty-three patients with DSD were cohorted together in patient areas in numbers of 4-5. In three of these areas, one agency mental health nurse in each individual ward was initially allocated to one patient identified as most at risk of harm to self/others, or absconding, but then was asked to oversee the other patients with DSD in the bay.

On two wards where there were individual patients with DSD, there appeared to be a staff member working in the same area but not directly making contact or responsible for patients with DSD. Therefore, the level of support appeared to fluctuate and be less visible or engaged during handover periods.

On three wards, patients with DSD were in single rooms each with an allocated staff member to provide constant observation. The staff members were a mental health nurse, an enhanced care healthcare support worker (HCSW) and a HCSW employed through National Health Service Professionals (NHSP). From the observations, it was not possible to infer how decisions were made about whether a qualified or unqualified member of staff should do the constant observation.

On one specialist area, two patients were placed by the nurse station in an open ward assessment area. This ward layout was different to other areas observed and reflected the speciality focus of the unit.

Post pandemic ward changes/interpreting the environment

Some wards had received some significant changes following the COVID-19 pandemic. Wards two, three and six had sliding doors in the sixteen bedded end allowing staff to isolate four patients together. I observed on four occasions, seven patients were calling out from behind these screens, and they appeared not to be heard. Some family carers were heard to raise concerns; they felt their family member could be neglected as they were unable to use the call bell. It was also noticed that the quietly spoken patients were not heard outside of the doors on six occasions.

How patients were observed to interpret their environment was complex, but the observations identified how the physical layout of the ward and patient bays affected a patient’s orientation and attempts to make sense of where they were.

During one observation, one patient said “I see these people all sitting here, it’s like we are in a church” (ward 6). This was a five bedded area; the period of observation was during a particular busy visiting period and there were several relatives sitting by the bedsides on chairs.

During another period of observation on ward 5, a patient described to her husband on the telephone:

> *“I am on a boat; the boat has just landed and I’m in a cabin with some other ladies”.* (Observation 5)

Ward 5 was a very bright unit, the lady was in a section away from the nurse station with a dividing wall, and the projector was displaying a film. In this position, the patients were separated from other ward activities and staff passing. This separation and sense of waiting with others may in part explain this woman’s interpretation of the environment.

The importance of lightening and the ability to adjust this at an individual level was highlighted by one patient, when seeing the observer, she gestured for me to come over, covering her eyes, indicating she wanted me to keep the curtain closed.

The importance of appropriate signage for patients that is clear can support wayfinding, reduce delirium and help with orientation. However, during observation on ward 7, it was observed how one patient with DSD, interpreted signage did not have the desired effect and impacted on him psychologically. The patient seemed troubled by reading the toilet sign and appeared to link this to his fear of being incontinent. During the observation, it appeared that being opposite the toilet door was unhelpful and was a trigger for anxiety about continence; he made several references to the sign throughout the period of observation. He was also having visual hallucinations/seeing signage differently, this was also linked to an emotional connection, for example a toilet sign was interpreted as a place where he felt ashamed. Following the observation, I felt it necessary to discuss this with staff. Nursing staff seemed to understand this and said that, before I arrived, the patient had been incontinent, and this had distressed him. They also said, “he often gets like this”. They explained that when they change him, they try to distract him by singing to him. Staff were and had adjusted their approach, not by changing his location but by how they provided care.

Wards are naturally noisy environments, especially around mealtimes when staff are preparing patients for meals, dinner trolleys are being manoeuvred into position, and food related conversations on the door happen upon arrival to the wards. Similarly, there were peak times for telephone activity and people arriving and leaving the ward between 4-7PM; calls were associated with decisions about patients' needs and movements. In addition to phone ringing, there were often queries around discharge from the bed manager, site team, matron and family carers. Telephone calls increased from pharmacy requesting medications to be collected.

Transport arriving to collect patients meant there were additional staff in patient areas while they were eating, requiring prompt attention and new patients arriving, often on a trolley with a porter and family member to be admitted. At this very busy time of day, it was noticeable that the level of administration support for the wards was reduced or absent. During all the observations, there was no ward clerk support, no discharge support and no-one designated to answer the telephones, often leading to extended periods when ringing phones were unanswered.

The observable impact on patients with DSD, of the telephone ringing and not being answered, was their increased anxiety and attempts to respond. With individuals often thinking it was their phone at home, the noise triggered a reaction for them to get out of bed to answer the phone. There were also episodes where patients with DSD reacted to other conversations happening near them. They were unable to differentiate between what concerned them, and the person in the next bed. This could mean they answered, thinking they were being spoken to; then, when no-one responded, not being acknowledged/answered caused distress.

Range and type of interactions during an observation

The number of interactions, patients with DSD had, varied widely with some requiring multiple contacts, often addressing certain behaviours like calling out or getting up repeatedly to leave the bay. During one two-hour period of observation on ward 1, there were 11 separate patient/staff/family interactions for one patient. Most involved providing reassurance in response to expressed needs; this involved staff repeating the same message, coming over to the patient, maintaining eye contact and reflecting back to the patient, mirroring what the person said in order to help them acknowledge they had been heard. Housekeepers provided additional support and reassurance on two occasions, this involved making conversation in a soft tone and offering a snack and a cup of tea. On one occasion, there was the need to intervene between two patients having a disagreement (both with DSD). There were also examples of how much activity happened around a patient that engaged their attention in different ways. During a second two-hour observation, there were 15 interactions observed, this included arrival of family members visiting individual patients (5), housekeeper providing clean water jugs, then returning to check menus and provide afternoon tea. Registered nurses attended to patient care needs, i.e. repositioning/toileting (4), responding to patient call bell (1), and administration and other staff walking through area.

On one ward (ward 6), there was minimal interaction with sixteen patients (four patients had DSD), observed only two occasions of a Health Care Support Worker (HCSW) outside of the sliding doors walking past with linen. This appeared to be because of the layout of the ward, four patients with DSD were isolated behind the sliding doors restricting their ability to engage with staff and each other. On this ward, there was not an opportunity to nurse the patients in a more open/visible area. While observing, I noticed how the HCSW was being proactive in her smiles as she passed by outside. One patient being observed, looked up and commented “she is very nice”.

During this observation, I witnessed those proactive interventions came from staff other than nursing. A Housekeeper (HK) was heard assisting with orientating patients, telling them the date and time and talking about the weather.

Supportive Interventions as a way of managing delirium

Staff were observed responding to patients with DSD by adjusting the physical environment, including attempts to reduce the lighting and noise level on the ward, enabling patients to walk often supervised by someone allocated to provide one to one care. Other approaches used were visual stimuli, such as the use of photographs to provide a way of connection to family, utilising other staff resources, staff (e.g. ward clerks) organising how they worked to be close to patients and companionable, doll therapy, access to music, and actively providing reassurance by touch, holding hands/and stroking or patting the patient on the top of the arm, back or hand.

Noting positive care experiences during the observation using an appreciative inquiry lens was important for this study. The observer noted a range of attempts to reduce anxiety and provide meaningful activity to support the person with dementia and delirium's hospital stay that otherwise may have been missed. There were distressing occasions when patients were observed having their needs overlooked, knowing however that there could be different outcomes and what staff were able to achieve provided important evidence to address these shortcomings.

How family carers interacted with their relatives highlighted the choices available to them in a ward environment and the place of sensory stimulation. The use of music as an activity to do with patients was observed to being played by family carers when visiting. Positive reactions in the patient, such as focusing their attention and creating a way of connection to emotional memories, led to the patient appearing more relaxed and content with an improved well-being and an improved interaction with the family carer, leading to a positive impact on maintaining relationships. The other patients were observed to enjoying this, witnessed by them tapping their feet, smiling and being generally more engaged. Music also provided a channel of communication, as exemplified by patients and family, leading to a potential reduction in caregiver stress and a means of social engagement and interaction when visiting. On ward 1, the observer noticed the Namaste room; Namaste is an activity used in advanced dementia to stimulate the five senses when communication is now difficult.

This included a sensory trolley with a projector, water/bubble column and a music system. The room also included some decorative wall art, activities such as dominoes, colouring books and baby dolls and soft bodied animals. At the time of the observations, on one occasion, the observer noted the sensory trolley in use.

Some sensory stimulations can reinforce a sense of focus and connection. During another period of observation (ward 1), a staff member was heard talking to a patient about her baby (doll), the patient had started to call for help, she commented on its clothing and asked about the baby's name. By providing a way of connecting between the staff member and the patient, and being something, staff could talk about, it was observed that the patient responded by smiling, becoming attentive to the baby doll and provided a means of distraction, pre-empting possible distress.

Staff and family recognition of and response to patient distress

The emotional impact delirium can have on a person with dementia is not often explored. An ethnographic study looking at agitation near the end of life for patients with dementia in hospital identified 75% of these patients presented as agitated, and a high percentage of these patients would have delirium (Sampson et al., 2019). During the observation, this was most noticeable in the severity and length of distress patients could experience. A patient with DSD was crying, responding to other conversations on the ward that were not directed at her, staff members talking to each other in raised voices or patients talking to their visitors, her distress increased going from looking sad, noticed in her facial expression, to loud periods of crying, raising her voice and using distressed language to others, and being sustained over twenty seven minutes. During the observation period no staff member was responding to her. The longer the patient's distress was not responded too, the level of distress increased.

> Patient continues to get distressed, saying *"I'm nearly 90 years old and I go to work every day, I'm in charge of children at the school, my parents died last week*" (visible signs of distress on face, looks tearful). (Observation/Field note 1).

At the end of the period of observation, when discussed with a staff member, the reply was "she's been like this all day".

During some periods of observation, staff encounters with patients focused almost exclusively on the patients' physical needs; these could either trigger agitation and distress or mean patients' distress was not addressed over the need to complete the task. How staff reacted and interacted with patients with DSD in these moments could be broken down into three approaches: reassurance, instrumental and proactive.

Responding to distress

Reassurance

In one period of observation, there was an unexpected medical emergency. During this disruption, the observer witnessed the HCSW remained on the unit with patients, checking on their well-being, offering drinks and responding to call bells. The HCSW demonstrated empathy and reassurance in one example, taking time to prepare the patient about the activity, using compassionate communication and loving touch (a Namaste intervention) during a personal care activity.

During another observation, observer heard HCSW say:

> *"Sorry to wake you up but we need to change you"* (Observation 7, HCSW). *Patient wakes and sounds anxious, noticed by the tone of her voice, she starts to call out, sounded distressed by the tone and volume of her voice".*

Observer heard HCSW trying to reassure her, one HCSW responds:

> *"Let me hold your hand, we will be as quick as we can then you can go back to sleep." (*HCSW, Observation 7)

This appeared to be an attempt to prepare the patient in anticipation of experiencing distress or pain.

> *HCSW asks "are you in pain?", patient didn't respond*. (Observation 7)

HCSW said to her colleague,

"She might be, she has contractures and a large pressure sore", (Observation 7)

Patient calling out "help me", ceased for a short while, then she started shouting and swearing. Staff did not communicate during this period and continued with changing the patient, refreshing the bed linen and repositioning her.

During another period of observation, when noticing two patients appeared upset, voices raised, packing up belongings and wanting to go home, HCSW'S were showing kindness by the tone of their voices and the explanation given to the patient and taking time to explain things; their calm approach was patient and helped a little to ease the distress.

Instrumental

There were many observed examples of staff providing instrumental care when dealing with how the person's behaviour focused on keeping them safe or contained over addressing possible reasons. In this example, a mental health nurse (RMN) was providing one to one care, observing a patient with DSD. Staff reported the patient was at risk of falling and was very delirious.

For thirty minutes the patient tried to remove his pyjamas, he was speaking in a mumbled voice, not able to articulate any understandable words; at this time, he was sitting in the chair by the bedside and made several attempts to stand up indicating he may want to leave.

Every time the patient attempted to remove their pyjamas, the nurse stopped them doing so. The nurse said,

> "Don't take your clothes off, you will get cold" (seven times). Once the pyjamas were back on, the nurse sat down again.

In this observation, there were no observed attempts by the nurse to discover what was prompting the behaviour. During several observations, it appeared the staff experienced difficulties understanding what the patient was trying to express/mean even with simple questions. Staff tried to adapt the way they communicated using short sentences. However, sometimes their interpretation and assumption that the patient's response was correct was misplaced.

An example of this during one period of breakfast observation (observation also highlighted the added challenge of cultural differences affecting instrumental care).

> Housekeeper came over to Bed 15 and said, "what would you like for breakfast?"
>
> *Patient replied, "I've had breakfast". Housekeeper said OK and walked away.*
>
> Observer intervened at end of observation and said patient had not had breakfast.
>
> When asked again, patient replied, *"I would like some Kellogg's".*
>
> Housekeeper didn't understand the word Kellogg's, (first language not English).

> *Patient said, "I went on holiday during the war with my mum and we had Kellogg's, I love my mum".*

Housekeeper did not respond and moved on to next patient. This was a missed opportunity to validate the expression of emotion and acknowledge the patient's feelings.

Proactive

Proactive care by staff/family carers were characterised by activities that included providing activity at visiting time, ensuring teeth were brushed, snacks and drinks were provided, and music was used to provide a channel of communication. Often these were related to the comfort of the patient.

> *RN talks to patients, checks on comfort, checks buzzers in easy reach, checking feet are tucked in, checking tables within easy reach, asking them if they are OK.*
>
> *Field note ref. 1:*
>
> *Patient walking along corridor accompanied by an enhanced care nurse. Nurse was talking quietly and providing comfort to patient, asked:*
>
> *"Which way would you like to walk, would you like a drink?".*
>
> Patient was not very responsive verbally, but from facial expressions appeared settled.

When family carers were observed to use music and photos, and the use of technology such as tablets and mobile phones, the following was observed:

- Music playing on mobile device. Sounded like spiritual music in patient's native tongue.
- Family carers, keen to show family photos to their relative. Lots of positive discussion heard, news about family members and encouraged conversation about events from the past. Call on mobile to various family members who in turn spoke to patient, patient responds by smiling and becoming more engaged and talkative.

- Relatives opposite use an iPad to play some music, observer notices other patients appear to listen and are enjoying this. Observed other patients in the bay responding to the music, smiling, tapping their hands/feet and interested and asking questions about the music.

Staff also used pictures and mobile phones to connect actively with patients' interests and family.

An interaction between a nurse practitioner and a patient with DSD underlined how noticing the patient and the objects left by family led to an affirming interaction.

Asks patient:

> *"Is this yours?" pointing to photograph album. "Can I have a look?", "This is lovely, do you like gardening?"*

Patient replies:

> *"A little, gardening can be quite hard, and I am not as strong these days". NP replies, "I look forward to seeing more pictures"*. The patient appeared content after this interaction, and I believe would have enjoyed the company for a longer period.

An enhanced care nurse also used pictures to encourage other staff to engage with the patient, this time providing them with a reason to talk and connect with her.

> *"Mary has been looking for her garden; she has some lovely pictures on her table of her garden. Would you like to come and see them?"* (HCSW, Observation 5).
>
> *Phone rings, RN answers this then RN takes phone to patient bedside, taking time to explain to the patient where John is "John, your wife is on the phone".*

Other attempts to keep people oriented and provide support to patients with DSD were observed, family carers too on two occasions, leaving messages and notes of encouragement.

> *"Mr Graham will visit you at 1.30pm" (note left on bedside table).*
>
> *"Keep fighting Dad, keep strong and come home soon, we love you very much".* (This had been left by the bedside of a patient who was very unwell).

In summary, the number of interactions to support a person with DSD and partnership with family carers presented as:

1. Family carers attempt to get an update from the nurse, however the nurse appeared reliant on the medical team to provide this (Field note 2). This reflected in observer over hearing two relatives commenting on poor communication in hospital.
2. Lots of discussion at the point of discharge, RN providing reassurance of who to contact with any concerns (Field note 5).
3. Providing regular contact with family carers who were unable to visit using the telephone (Field notes 1,5,6,7).
4. Staff ensuring handwritten notes/directions left by family are read out to the patient regularly and were within reach (Field notes 1,5).
5. Staff informed observer and observer read, This is Me, completed by son at visit, staff commented about the importance of this.

Observer also noted how the impact of COVID-19 and anxiety surrounding this may impact on family carer visits. Two family members came to the door to visit a person with dementia, asked if there was anyone with COVID-19 on the ward, and then declined to visit. RN provided them with an update at the door and family carer left snacks, belongings, hearing aid/glasses and a stick.

Summary of key findings from the discovery stage

1. The allocation of patients with DSD to the right ward, with the right level of staff, and staff trained to care for patients with dementia varied.
2. The ward layout and design had a significant impact on the person with DSD, their ability to feel connected, to feel included and to be stimulated, and for nursing staff to have a strong oversight of their needs.
3. Environmental triggers such as unavoidable noise, and noise due to the volume of staff, visitors and ward activity caused heightened distress in people with DSD.
4. The repertoire of skills staff used to support DSD were varied but included distraction techniques and a calm and compassionate approach.

5. Staff’s ability to connect and provide care for a person with DSD was dependant on their role, the environment and their knowledge and experience.
6. Family carers used music therapy as a way of connection, often engaging with other patients without visitors.
7. Ward signage, despite attempts at being dementia friendly was open to interpretations dependant on the person with DSD and their symptoms.

Staff used several strategies to facilitate making connections with people with dementia that, in turn, helped build relationships with the patient and their family carer.

Chapter 5 - Discover and Dream Phases

Introduction

This chapter presents the findings and outcomes of the Appreciative Inquiry (AI) process as they progressed from discover to dream and during some interviews thoughts around design and destiny were discussed. The design and destiny stages will be continued and explored in future work resulting from the findings of this thesis.

The chapter includes:

- A description of the study setting and participants.
- Summary of interviews -Table 26.
- Key factors identified when caring for patients with delirium superimposed on dementia, broken down into the following areas: recognising the patient with DSD and their families, the emotional impact of DSD on the family carer, the person and staff, system interventions to support the person with DSD, post pandemic barriers and workforce challenges, and practitioner working with family members to support interventions with the person with DSD.

Some data are presented in tables, with example excerpts from observational field notes and interview transcription aiming to represent the voices of the participants. Findings from the discovery stage of the 4D cycle (non-participant observation) form the basis for the interview stages of the study where Discover, Dream, Design were explored. Appreciative Inquiry findings from interviews using a story telling approach and emotional touchpoints.

Setting

One district general hospital was recruited for this study. The hospital was comparable in size to similar hospitals that provide the same service or similar. The ward staff who participated in this study worked on the hospital site across different ward areas. Dementia care was delivered across all inpatient wards, with most patients with dementia cared for across 4 wards whose specialism was older people/medicine.

Study Population

The data collection period ran from October-December 2022. There are approximately 440 Registered Nurses (RN) and 195 Health Care support workers (HCSW) employed across the inpatient wards. Thirty-one registered their interest to take part in the study but, for various reasons, only 3 took part. 35 healthcare professionals and 11 family carers were invited to take part in the interview. Thirteen people were interviewed which consisted of 3 registered nurses, 1 doctor (also brought insight as a family carer), 4 healthcare support workers (HCSW) of which two were also family carers, 2 chaplains and 3 family carers. The interviews were carried out face to face at the participant’s place of work/research site and the family carer interview at their own home. Staff interviews took an average of 45-60 minutes. Interviews with relatives took slightly longer with a mean time of 55 minutes. The interview technique drew on the use of emotional touchpoints and encouraged a story telling approach that allowed participants to focus on what they saw as good or significant episodes of care.

There were recurring themes running throughout the interviews. These can be summarised as: the impact of a clinical environment, staff balancing relationship centred care with patients’ technical care needs, communication between staff, patients and family, complexities of caring for someone with delirium superimposed on dementia and the need for education, the importance of addressing the fundamentals of care, carers’ distress, person centred care and staffs’ experience of caring for people with dementia. Summary of interviews, Table 27.

Table 29: Summary of Interviews

Staff Member	Family Carer	Key positive Outcomes	Areas for Improvement
1	No	Communication Compassion Knowing the patient Support from Dementia CNS Advocate	Recognising dying Emotional distress for FC who are also HCP
2	Yes	Knowing the patient Enhanced care Activities Non-clinical staff supporting patients with Dementia Staff made friends with mum Relational care Frailty service	Quality of 1-1/enhanced care Communicating with people with Dementia Lack of delirium awareness in community among MH team Delay in dementia diagnosis
3	No	This is Me Relational working Person-centred care Pets as Therapy Time when providing enhanced care Namaste Care Training Music therapy Volunteering role Namaste intervention (gives patients another focus), increases nutrition and hydration intake Providing comfort, holding hand provides reassurance Interactive technology Dementia and Delirium simulation helped	Loss of specialist Dementia ward Loss of space to deliver Singing for the Brain Some staff don't know how to respond to people with dementia Lack of sensory equipment

		Talking has reminded staff member of the good we can do	
4	Yes	Personal experience has influenced/improved understanding Staff quite receptive to following delirium pathway before requesting MH MH have good relational working with frailty service Delirium screening tool easy to use	Medical staff lack knowledge and awareness of DSD Treatment in hospital for DSD variable Frightening experience for mum and staff Pain sometimes not addressed as a causative factor of delirium post op More training needed for doctors Not enough time to screen all patients who meet NICE criteria
5	Yes	Communication Relational Care Fundamentals of care Implementation of project in ICU (complete body hygiene not during hours of 00:00-06:00) Learning from patient stories Talking to the patient even though sedated in ITU	Consistency of information given to family carers Understanding of DSD Nutritional support Knowing the patient Lack of delirium knowledge in past, resulted in overuse of sedation Need more investment in delirium/national drive Cultural differences in education/experience around dementia More awareness for therapy staff (too often report “patient won’t engage”) Staff resistance to visiting, despite dementia carer’s policy.
Six	No	Enhanced Care Team (ECT) Education Interactive technology Compassion, empathy and kindness at the heart of some staff Natural empathy	Quality of handover Ward staff acceptance of ECT Staff acceptance/interpretation of enhanced care Training not put into practice Staffing

		Training Some staff provide activities/cohort patients, watch films Relational care	Hard to evidence qualitative evidence of impact of EC/empathy Delegation of enhanced care staff Communicating and reassuring patients with DSD challenging
Seven	No	Dementia training Namaste Activities Working with Dementia CNS 1-1 care, patient and kind	Nurses' ability to recognise distress (task focused, no time, focused only on clinical tasks) Staffing
Eight	No	Training More spiritual awareness, books to encourage discussion Music therapy Doll therapy	Difficult to understand what's real for the person, how to respond Cultural difference, lack of understanding of dementia, still taboo Staffing
Nine	Yes	Relations with family (asked that patient wasn't discharged in the evening), staff complied	Deconditioning following hospital admission Impact of lockdown Multiple episodes of delirium Seeing dad scared and crying Coming home in the dark, link to worsening delirium Restrictions on visiting
Ten	Yes	Enhanced care nurse provided support	Lack of understanding of DSD in community Environment of hospital setting Staffing No explanation about delirium
Eleven	No	Education Role modelling Preceptorship programme	More cultural awareness (Nurses who lack Dementia experience/education from overseas) Lack of senior support "We call it growing old", how dementia is understood in other cultures

			Understanding of delirium existing on top of dementia Passing exam (clinical skills) priority over person centred care
Twelve	Yes	Support from Dementia CNS Virtual visiting service	Visiting restrictions during COVID-19 Witnessing rapid decline during delirium/emotional distress Need more education for families
Thirteen		Embedded in HCSW supporting people with D and DSD Relational working Challenge to self to inform carers about support When helping carers "it fills like I care" Caring makes me feel better Feeling proud, have knowledge to discuss delirium, helping carer Training/Simulation Proud of my communication skills/dementia Friendship/strategies Intellectual understanding of "being in their shoes" Role modelling good example	

Demographic data

The family carers' ages ranged from 36 years to 81 years (Table 28). Family carers all described themselves as white British. Two of the family carers had a professional role at the study site but applied to take part due to their family carer role. Their professional role did not include working with patients with dementia.

The ten healthcare professional ages ranged from 26 to 59 years (Table 29). Some of the HCP described themselves as white British (n=6). The other HCP staff at the hospital described themselves as African (n=1), American (n=1), Pilipino (n=1), Kiwi (n=1).

Table 30: Family Carer Demographics

Family Carer Demographics					
Family carer	Gender	Age	Relationship to PLWD	Length of relationship	Had a professional role at study site
Family carer 1	Female	48	Daughter	48	Y
Family carer 2	Female	81	Wife	60	N
Family carer 3	Female	36	Daughter	36	Y

Table 31: Staff participant demographic information (some also had caring role)

Participant Number	Cultural Background	Male/Female	Length of time in role	Age Range	Participant role recruited for as staff	Had additional caring role
1	English	Female	10 Years	30-39	Staff member	N
2	English	Female	16 Years	50-59	Staff member	Y
3	English	Female	11 Years	40-49	Staff member	N
4	English	Male	30 Years	40-49	Staff member	Y
5	Kiwi	Male	23 Years	50-59	Staff member	Y
6	English	Male	32 Years	50-59	Staff member	N
7	English	Female	3 Years	50-59	Staff member	N
8	Nigerian	Male	4 Years	30-39	Staff member	N
9	Filipino	Female	10 Years	30-39	Staff member	N
10	American	Female	2 years	20-29	Staff member	Y

Family Carer=FC

Health Care Professional=HCP

Staff participants worked in a range of roles and designations which included: Registered Nurse, Heath Care Support Workers, Chaplains and Nurse Educators. Six staff identified themselves as working across inpatient ward areas, which included dementia care and all staff including the chaplaincy staff had experienced working in or supporting patients with dementia. Two registered nurses now had a nurse educator role but kept up to date with clinical practice and provided direct patient care during periods of redeployment.

Overall, of the ten staff participants, seven (70 per cent) were female, which is representative of the 80:20 female to male gender ratio in the wider health and social care workforce in the United Kingdom.

Staff participants had worked there between 2 and 31 years with a median of 14. During the discovery process, 4 of the HCP participants disclosed that they were currently caring (or had recently cared) for a close relative living with dementia.

Recognising the patient with DSD and their families

The experience of delirium can have a lasting impact emotionally on the family carer. The use of emotional touchpoints enabled people to address from the outset the moments where their feelings and lasting memories of being with a family member with DSD. They were an effective way of exploring and understanding what good practice was and what should be done to improve the experience. Although the approach to the interviews was to focus on examples of good care, family carers described how they were distressed and alarmed when the person displayed out of character and common symptoms of DSD, such as resisting care, hallucinations and cursing. They described the experience as frightening and upsetting when they did not know how to respond to changes in behaviour and cognition they witnessed. Family carers did not find it easy to identify actions or situations that had been helpful. A range of symptoms were described with varying degrees of severity and anxiety.

> FC1 *“He got much worse in himself, he started being unbalanced, it was very quick, we couldn’t figure out what he was saying, he became lost in his own body. He didn’t understand where he was, then he would get moments of clarity, and you could have a conversation”.*

A picture of restlessness accelerated confusion, and distress was described by another family carer.

> FC2 *"We had a terrible weekend, he didn't know what he was doing, he was watching the three nations on the television, he wanted the England flag and the Welsh flag, and he wanted them off the TV. He didn't know what was going on, he spent the whole night thrashing around completely".*

Although the family carer had witnessed behaviours, prior to hospitalisation, previously associated with her husband's dementia, this presentation was completely different because she couldn't reassure him. The family carer described feeling shocked, sad and upset by the events that led up to hospitalisation, she said "he was completely off his head".

One family carer explained how she only understood afterwards that her relative's behaviour was due to DSD, without these insights at the time she described how she interpreted it as deliberate, a choice by her relative to be difficult and resist care.

> FC2 *"I certainly didn't see it, didn't recognise it, when I looked at him. I didn't see delirium; I just saw awful behaviour basically*".

Most understood what they were observing was different to their relative's dementia. They also described how an episode of delirium had had long term consequences. One family caregiver shared her experience of noticing a rapid decline in her father when he had a urinary tract infection. It marked a significant change in his cognitive capacity and how family members were able to connect with him.

> FC3 "*He started becoming really unbalanced, he went down really quickly, he didn't understand what we were saying to him, he didn't, he became so frail ".*

Another relative similarly marked the experience of DSD as a turning point.

> FC2 *"When he came home, we got on with it and got our lives back together. He never really came back to us, the man we knew never came back to us, he never went back to where he was".*

It was evident that this experience, despite being some time ago, remained fresh in their minds. They felt helpless, witnessing the changes an acute illness and period of hospitalisation can cause, not knowing how they could alleviate the situation. These family carers were able to describe the impact of being emotionally unprepared when witnessing their loved one displaying distressed reactions. They spoke of being unable to cope.

When trying to make sense of what had happened when their relative had been in hospital, family caregivers described difficulties accessing information about DSD. These family caregivers described feeling alone and how, learning from others in the same situation, would have been helpful. Family caregivers wanted to feel prepared to care for the older person. One family caregiver, describing her feelings of isolation led to her reflecting on how peer support has helped her address her relative's dementia care needs. She suggested that these kinds of opportunities to talk about what the symptoms meant could be similarly helpful:

> FC2 *"It's hard, you don't see anyone else in the same situation, you can't talk to other people about it, it's just we learn a lot from each other don't we, like at our group (describing attending a dementia friendly coffee morning). I like approaching things if I can understand it and I can react to it better… The worst thing was…I didn't have a clue about delirium".*

While delirium educational materials were observed to be available and present in some areas, they were not widely distributed and were not referenced in interviews.

The importance of listening to family carers was illustrated by one account where, drawing on their previous experience of a hospital discharge late in the evening, it gave the family an expertise not otherwise accessible to staff. The family knew what was important for improving her father's condition and reducing his fear. It was an example of good practice with family being able to work with staff to improve the experience of discharge and manage the risk of delirium.

> FC1 *"When we got him home, it wasn't until the evening, he didn't know he was in his own home, coming home in the darkness and at night, it didn't help, he's been in hospital a few times since then. Mum has always maintained and said to the hospital, please don't discharge him in the evening, because you know he will get delirious when he comes home, he will be scared and upset. It was horrible to see Dad, an ex-footballer, a golfing man, very intelligent, cry and get upset about being in his own home (sigh), so yes, we are mindful of that now, and we always feed that back to the hospital".*

How staff perceived the nature, impact and consequences of the ‘problem’ of delirium on the patient, their family or the ward routines affected how they sought to manage it. Staff who understood the significance of patients' 'acute' or 'temporary' confusion described and were observed to have a more proactive approach, actively seeking information from family and friends to determine whether the confusion was longstanding or recent. Others were less able to demonstrate they recognised the significance of different behaviours and how delirium differed from dementia. In these situations, delirium could, like family accounts, be mistaken by staff for bad behaviour.

Although family carers could, based on their prior knowledge of the person, discern a difference between dementia and delirium, even if they did not know how to respond, some staff were less perceptive. They used the terms ‘confusion’ and ‘acute confusion’ interchangeably, often not differentiating between acute confusion and dementia. The consequences were that search for a cause might not be pursued by the healthcare practitioner. In this quote the member of staff acknowledges that, in previous roles, they had not always recognised the symptoms.

> HCP5 *“I look back to my time in ITU and reflect on things, and think, oh yeah, that guy who was behaving oddly, they probably had delirium, or they had hypoactive delirium. It’s easy with hindsight, I feel bad now, because I didn’t know it then, what I know now”.*

Dementia and delirium are closely interlinked and even specialists may not initially be able to differentiate. The following quote highlighted the complexity of identifying delirium or dementia, especially during an acute admission to hospital when the patient arrived without a dementia diagnosis.

> HCP4 *“There was one gentleman on the ward, he was known to have some cognitive impairment on admission, wasn’t picked up outside the hospital, admitted for hip fracture, mildly confused but post-surgery he was extremely confused, initially attributed to cognitive problems, therefore they decided he had dementia. So, we (mental health) treated it as delirium. It turned out, he did have dementia after further testing, worse after the surgery, but there were occasions he was delirious too, attributed to cognitive problems, this might not have been picked up”.*

In summary, this quote was stating they had assumed it was delirium when it was dementia all along, but with an overlay of delirium, therefore raising an important statement that DSD is so complex.

The range of symptoms that were described and observed to trouble staff the most were patient anxiety, aggression, lack of sleep, hallucinations, deconditioning, impaired cognition, suicidal thoughts, crying and paranoia. Aggression and/or refusal to participate in treatment could be interpreted as ‘lack of engagement’, resulting in the patient being perceived by staff as unsuitable for rehabilitation or berated for ‘inappropriate’ behaviour. When staff conflated the symptoms of delirium and dementia, this was a source of heightened anxiety and perplexity among caregivers/relatives as the suddenness of the change and the strangeness of the behaviour of their relative was not recognised by staff.

The following provides an illustrative example of the non-recognition of delirium on a background of dementia and a staff member’s limited response to what they interpreted as disruptive behaviour (walking around).

> HCP2 *“There was a gentleman, he had younger onset Lewy Body dementia, he wasn’t violent, he was quite young, his wife was fantastic, he liked to walk around. When she wasn’t there, he needed a 1-1, it’s sad to say and I did raise it to the nurse’s supervisor, he was an agency RMN, he just sat there blocking the door, he didn’t interact with him, he was like a prison guard blocking the door”.*

Walking with purpose can be associated with dementia, the above quote demonstrated that while the RMN response was not appropriate, the HCSW interviewed may also have not differentiated between delirium and dementia.

The use of registered mental health nurses employed by the trust through an agency was highlighted by this HCP as one reason why the professional response was inappropriate because they were not educated to recognise clinical signs of delirium. During the non-participant observation phase of the data collection, agency staff were not integrated into the usual ward routines/handovers therefore there were no opportunities to learn about the patient and what was normal for them.

What many staff didn't report were the symptoms that caused emotional distress and those symptoms of hypoactive delirium. It was noticeable that, when HCP had personal experiences of family members with dementia, they were more likely to differentiate between behaviours linked to the person's dementia and those caused by delirium.

> HCP1 *"Some of us have been to the delirium conference, some of us to the delirium training and it has made us aware of things to look out for, and also how to reassure the patient. But for me personally, it made me realise how to support the family. Sometimes it will be like "my mum is going round the bend", and I will say, "no, your mum has delirium", "your mum will change, you just have to go along with it". The relative will say (in response to a cat being seen on the bed), "don't be silly there is nothing there", and we will say "No, don't say that, say don't worry and we will get rid of it".*

Another HCSW described when talking about delirium and impact of hospital admission.

> HCP2 *"I can recognise it in my patients, I think it helps you to understand more, if you know your patient and know it could be delirium, simply from being there, let alone medication or change of food".*

When describing the importance of knowing the patient, addressing the importance of hydration and nutrition and meeting fundamental needs for a patient with DSD who had been declining personal care needs and food refusal due to new hallucinations.

> HCP2 *"I used to come in a little early, so I could help the mental health nurse give her a wash. I would bring her in a banana as well, she like bananas and satsumas, it's just a matter of knowing what people like".*

These insights supported the delivery of fundamental nursing care through placing emphasis on the importance of ensuring the patient with DSD was able to move, sleep, rest, eat and drink, to be clean, feel safe, make choices and feel respected as a person (Maslow, 1970, Collier, 2019).

In this quote, the HCP reflects on what staff focus on, describing a situation where a patient was acting strangely but was not presenting with symptoms staff found challenging. She described an approach that did not rely on first impressions.

> HCP9 *“It does sound strange, but constipation in older people does cause cognitive changes. I was taking care of the patient, and she did not understand what I was saying, she seemed a bit spaced out actually. I met her before her operation and she wasn’t making any sense, but after we sorted the constipation out, she was a different person actually. It just made me think if we are looking at the person holistically, it’s important not to make a snap judgement when you first meet the person*”.

As well as staff with personal experience of caring for someone with dementia, a person’s professional role could affect what they noticed. This example illustrates two findings, the value of multidisciplinary as well as family involvement and how some kinds of delirium are easier than others to overlook. A chaplain visiting the ward noticed how unusually quiet a patient was; it was subsequently discovered the woman was manifesting a hypoactive sub-type of delirium.

> HCP7 *“I was about to leave the ward and there was another patient in bed, who I just noticed was very, very quiet and just sitting there looking around. She was obviously very alert and looking around, but so quiet and wasn’t saying anything. So that gave me cause for concern, I asked her how she was feeling, she replied “I’m scared”, so this is a lady who does have dementia, and she was feeling scared, and I asked her if she knew why, why are you scared, and she replied, “because they are angry”. She was able to talk a little bit more and say, “they are shouting, and they are angry, they might be angry with me”. She said, “but I like you, you have calmed them down a bit”. So yes, this is a lady with dementia, whom I was told after, had delirium, she was very sensitive to the atmosphere of the ward, and I found her like this. It was upsetting because I felt that if no-one had taken the time, she could have been left there feeling scared”*.

When asked what was it that enabled the staff member to recognise the patient’s distress, despite the presentation of being very quiet, they responded:

> HCP7 *“I think I have the luxury of more time, and my role is to get alongside patients, but it’s also about noticing, noticing body language, tone of voice, what it is that is telling me about how someone is feeling”.*

Time here is described as a luxury, where within their non-clinical role the chaplain had the opportunity to recognise and respond to distress and described this as their core work. The observed pressures and priorities of the ward and many human factors possibly affected how easily nursing staff were able to similarly notice and provide care.

Emotional Impact of DSD on the person, the family carer and staff

The interrelation and interpretation of DSD versus Behavioural and Psychological symptoms of dementia (BPSD) poses huge challenges and consequences for the patient. Often receiving pharmacological intervention (Calsolaro et al., 2021) for the management of symptoms, which then masks the symptoms of DSD and for the patient who is already cognitively impaired.

The staff who recognised the impact of DSD on family carers were not necessarily clinically qualified. The unqualified staff recognised the emotional impact of delirium on the patients and felt the emotion too themselves.

> HCP8 *"It's a difficult experience for them because they are not in charge of what is happening to them…., so that confusion, that delirium that change in personality is very difficult for them. And sometimes difficult for me too, as a person, to be where they are. Looking at the woman crying made me emotional too".*

During the period of data collection, the wards were working under pressure to prioritise key tasks (e.g. medication rounds and discharge planning) within a situation, staffing shortages, constraints (e.g. unable to safely supervise a group of patients, often described as cohort and time to gather person centred communication). This meant that acute care nurses appeared unable to place a high priority on addressing DSD care in relation to their other nursing tasks.

The non-participant observation work carried out prior to interviews with staff identified 17 patients with DSD with distressed behaviour on their wards. There were two patients where this was constant throughout the observations and the remaining had episodic events consistent with DSD. One woman was verbally more distressed for a prolonged period and one man, while noticeable to the observer, was extremely distressed; this was not noticeable to staff passing by. He was extremely distressed, evidenced by being quietly withdrawn, exhibiting paranoid behaviours such as talking to self, and the anxiety increased the more he spoke, talking to people/things that could not be seen and having visual hallucinations of animals and creatures that were frightening. Distressed behaviour was defined as the following:

1. Calling out
2. Crying
3. Displays of anxiety and uncertainty about their environment
4. Resistance to personal care
5. Apathy
6. Verbal displays of distress, such as cursing

Staff response to this distressed behaviour varied and, during the observation phase, this depended on the ward and the role of the HCP or staff member response. During this period there was not a HCSW in the area and care was provided by RN and Nursing Associates. During one period of observation on ward x, I noticed a patient exhibit a prolonged period of distress lasting for 19 minutes that appeared to go unnoticed or not reacted to by some staff. This distress included calling out “help me”, calling nurse, talking to self, wanting to go home, talking to bedside curtain. A domestic was the first person to respond to this when offering a cup of tea, followed by a HCSW after 19 minutes asking the patient if she was alright. In the background, RNs were dealing with drug rounds, and one was heard talking to relatives asking for a “This is me” to be completed.

There were multiple examples during the observation of registered nurses providing person-centred, fundamental care to patients, for example addressing personal care requests, providing extra blankets, tucking in feet. However, they were observed not to engage with the patient with DSD and appeared able to disregard their distress and focus on other work or less demanding patients. Although qualified staff, when interviewed, did not reference a lack of knowledge of how to respond to patients with DSD or demonstrate a self-awareness that they appeared to be engaged in avoiding behaviours. My understanding and reflection identified that it appeared they either found them too complex to respond to or were actively avoiding becoming involved in a situation that would be time consuming and affect their other work.

System Interventions to support the person with DSD (collapses three into one that focus on environment)

Previous studies on what supports people with dementia in hospital argue for an environment that supports the patient in terms of orientation, activity and stimulation. This includes the use of different temporal orientation aids, such as clocks and calendars, and staff who have the knowledge and skills to support patients with dementia, particularly around addressing behaviours that can be challenging in a ward setting (National Dementia Action Alliance, 2021). Participants in this study were aware of these findings and recommendations but emphasised that the complexity of delirium when superimposed on dementia provides an additional challenge when trying to manage the environment. One staff member described using a questioning approach to reinforce good practice and reduce the risk of delirium, checking what the experience of being on a ward might feel like.

> HCP5 *“These are the questions you need to ask the nursing staff, have you provided a calm environment, are the lights dimmed, is there a decreased sensory stimulus, that’s what you need to do”*.

Considering the surrounding environment and how this contributed to the person with DSD’s distress and disorientation were identified during both the non-participant phase of data collection and interviews. During the non-participant observation phase however, staff did not demonstrate by their action’s insight into the challenges and adverse stimuli the environment placed upon the patient. It was however difficult to interpret as to whether staff noticed the adverse impact of a noisy ward, saw this was something they could change or if they just accepted this was how the ward was organised.

In contrast, staff interviewed in this study appreciated what had worked well in terms of utilisation of space and the opportunities a dementia friendly environment provided. The following quotes suggest that some participants having seen adaptations in two wards have beneficial effects, believed in the benefits of providing people with dementia a dedicated space apart from other patients to reduce the risk of delirium and support orientation.

> HCP3 *"I would like to see a proper dementia ward where the majority of patients would go. I know it would be really hard work, but it would be so rewarding, like when we had G ward. They had that massive lounge where they could do activities. They had lots of paintings on the walls and had like a bench in the corridors of the ward, because sometimes when they are walking up and down, they get tired, so we should just allow them to sit in the corridor……It was separate from the main hospital, it was meant to be a Dementia and Palliative care ward. Sometimes we did get patients with difficult behaviours, especially when they have delirium as well. But it was good because we had a large lounge, we could take them into the lounge, let them walk around and they were quite safe".*

The need for patients with dementia to be occupied and to have the space to walk around safely, with opportunities for social engagement, were seen as likely to mitigate behaviours triggered by being in a strange and possibly threatening environment. Although during the period of observation there were few examples of these suggestions being enacted by staff.

The following quote also considered the impact on other patients when people with DSD were restricted to their bed or bay.

> HCP1 *"Don't think a general ward in a hospital is conducive to our dementia patients' sense of well-being. I don't think it is easy for other patients, I have seen other patients very upset. And other patients' families insisting that the patient with dementia be moved because they keep shouting out, swearing or being aggressive, or have wandered into their loved one's bed space and taken something that doesn't belong to them because they don't know what they are doing, I just think it is hard".*

The previous quotes illustrate two complementary ideas about how a ward environment can be managed to benefit both patients with DSD and other patients. Patients with DSD need space, space to be taken to enable them to walk safely and have access to activity that upholds person-centred care and a recognition of interventions to assist with DSD. There is also a desire to stop patients without DSD being disturbed or making complaints. Health care professionals were aware that some patients may be unkind to patients with DSD and lack understanding of their needs. HCPs in the interviews wanted to protect them from this.

During the interviews, family carers gave attention to the physical hospital environment in terms of design, interior and space. When they were sharing their experience of the physical environment, there was an awareness of what was likely to be helpful for people with dementia, for example lights, signage, space and sounds. Most family carers felt lack of space contributed to delirium because it added to their relatives' feelings of disorientation.

> FC2 *"What you need is a bit more space for people. Space is a premium. They couldn't put another brick anywhere and that wasn't their fault. People need space. Yeah, especially when they are that ill, being confined makes them more confused, it wasn't dignified".*

The previous quote illustrates that family carers' insights and experience of space, identified that for the person with DSD the feeling of being confined, being hemmed in, adds to the confusion already experienced. This was not mentioned by staff in the interviews. During non-participant observations, it was particularly noticeable that space between beds was limited, particularly on the wards that had undergone refurbishment following the pandemic, with the added barrier of isolation doors.

The idea of more space seems to suggest space is good if it provides a resource, for example a space to walk and be taken to. Staff members gave examples of specialist areas that had been designed to meet the needs of older people by creating more lighting, decorative wall art, dementia friendly signage and space for activities. Despite most wards having appropriate dementia friendly signage, this did not guarantee orientation and could add to a person's distress. For example, a person with DSD in a six bedded bay became distressed, responding to the telephone ringing and not being answered, and not recognising the sign above the opposite bed, assuming she was at home and responding to conversations heard on the TV.

This contrasts with the experience of another patient, underling how even signage held different significance for patients with or at risk of DSD. Here the importance of adequate signage to improve orientation was described by one family carer.

> FC2 "*Yeah, but he can still read. So, he spends a lot of time reading. He will be grounding himself. I always call it his grounding himself by looking at what's around it and what he can read off the walls*".

These findings confirm both the importance of correct signage, and an ability to recognise when it is and is not helpful. As the findings demonstrate, their value needs to be carefully considered and linked to each patient's understanding of where they are and what is happening. The desired impact that lighting and space could have, in providing reassurance in an unknown environment, could affect people differently.

Brightly lit open spaces were not always seen as a way of reducing the risk of DSD, as is reflected in the quote below:

> HCP2 "*I find it very big and open; I don't find it comfortable to be honest, and I find it bright. The patient with dementia would definitely be at risk of delirium on that ward".*

The perception of what is required to create a dementia friendly space may differ dependant on HCP experience and knowledge, particularly when considering the impact of delirium. The interviews revealed a lack of discussion or reflection between practitioners about what did, or did not work, for individuals with DSD. Individual staff members held different and seemingly untested views about what was beneficial.

During the observation and interviews, it was noted that some wards would move patients who were agitated to a side room; a strategy used to control and adapt the environment to support the needs of an individual participant.

> HCP4 *"I have found on some of the wards, without even asking, people have been moved to a side room, clearly they are being agitated by all the activity around them in a busy shared room, moving someone into a peaceful place and approaching them in a very calm manner, again not always suitable on*

> *these busy wards, but there seems to be a kind of awareness that those measures are helpful".*

Their assumption was that this was to benefit the patient although it could also help to provide a less disruptive experience for other patients. During the non-participant observation phase and interviews, there was discussion around the appropriateness of placing patients with dementia in designated areas to support person-centred care. What was not addressed was the impact on doing this defining people with DSD as "others", to be kept apart, and whether the absence of stimulation or staff presence contributed to their confusion.

Staff described ways in which they managed the physical space to create an environment of calm, for example a sensory room on the ward, and replicate the change from daytime to evening.

> HCP1 *"At the moment we have got a bay of 4, we take the bubble lamp in every evening because it creates a quiet atmosphere to settle them down".*

> HCP1 *"In the evening, around 5.30 after supper, we dim the lights and pull the blinds down, we try to give the feeling it is night time, time to rest and be calm, I try to ask the other staff not to make too much noise".*

Additionally, the hospital adapted the physical space to make use of the single rooms, creating a quieter and more peaceful environment. Some of the rooms have been decorated in a calming manner, with colours known to promote wellness and wellbeing, encouraging family to bring in familiar objects and photographs to help the patient feel more at home. This person-centred approach was recognised as important and involving family carers to help settle and orientate the patient is discussed in the following statement.

> HCP8 "*If family members can bring in pictures, it can also be like a presence, to make them not to forget, like the patient who said she had been abandoned by her family. She mentioned that herself, I don't have any family, they've left me, I don't have any pictures, my biscuits have run out, no one is here to stroke my hair or hold my hand. So, I think something that can help remind them, something they can see, a visual something is very important".*

The observation and interviews did not suggest that there was a common strategy that practitioners were implementing together in their day-to-day practice. This nurse describes an "awareness" of what could work well, but acknowledged this was not being done strategically or systematically:

> HCP6 *"As we are refurbishing the wards, we are touching on it, but we are not doing it on a wider scale, so we could probably for our patients with delirium and dementia, the way we lay out the wards, things we put on the walls could really make a difference".*

The following quote illustrates staff were aware that there is a national drive, when designing new hospital builds, to ensure they integrate a dementia friendly environment. Although ideas such as a bus stop on a hospital ward, when patients already want to leave are questionable and difficult to sustain in an acute setting.

> HCP6 "*I was on a national meeting yesterday about new hospitals and they are trying to set a template, in what it should look like and what it should have in it, and this was in relation to falls, but obviously a lot of that is about being dementia friendly. They had things like, you know, seats halfway down the ward, so they could stop and sit somewhere. Somebody put on there a couple of our care of the elderly wards have a bus stop, halfway down. I know we have the big murals on the wards. And it was really interesting, something I had never thought of, it was really useful to know, when you have got a single room, have the curtains on the outside, so you can pull the curtains back if you need to, rather than going in and disturbing the patient if you don't need to, some hospitals have built that in, having them on the outside rather than in, and just the way the hospitals are laid out".*

Layout, and how this could be improved, has been addressed in some ward environments, particularly the newer part of the building and one focusing in on frailty. Some staff referenced a time when patients had a choice about where they sat and ate:

> HCP6 "*I think losing day rooms was a terrible thing, because to a degree, we are making patients, patients, because there is nowhere for them to go. They either sit in bed or sit in the chair by the bed, and in the good old days, certainly*

> *when I trained which was a long time ago, you know if patients could, they got up and walked to the dayroom for their dinner".*

Patients, who used to be on the ward for days, are now day cases or next day discharge and during the period of observation the admission and discharge of patients accounted for a lot of qualified staff time.

Earlier in the chapter, family carers talked of needing to understand more about delirium. In the interviews with staff, key issues highlighted were concept ambiguity regarding what delirium is and is not, lack of knowledge and education, and inadequacy of resources to support nursing care. Nurses stated that historically, from past clinical experiences, they had been unaware about the process and presentation of delirium and on reflection, following gaining new knowledge in delirium, they recognised this led to difficulties in understanding their patients' behaviours and in connecting with the patients and their reality. Lack of knowledge and education were noted to be a major impediment to meeting patient needs. The following quotes help to illustrate this theme and a lack of shared learning across the multidisciplinary team. There was also confusion about who is the most knowledgeable in addressing DSD and should oversee decision making.

> HCP5 *"I think everybody, there needs to be a common awareness, if a more junior person knows about it, and a more senior person doesn't recognise it, then they need to speak up; I know it's easier said than done. The delirium screen involves several factors, awareness of the person's mental health background, history of how the person is presenting, blood tests which often do require a doctor to interpret. There needs to be a strong medical oversight, it shouldn't just be left to the nurses. Inter-professional learning has to be mandatory, has to be protected, so I'm talking about the doctors, therapists, nurses, pharmacists, dieticians etc., all learning together so we understand each other's boundaries. When I talk to medical students, after the delirium scenario relating to a physical trigger, the feedback is generally very good, they get nothing like that in medical training, so in a sense we are teaching them what medical school isn't"* (Registered Nurse/Clinical Educator).

Staff shared information about the impact of experiential learning through delirium simulation training had on them, particularly describing new insights about the emotional impact experienced by family carers.

> HCP1 "*Some of us have been to the delirium conference, some of us have been to the delirium training, it's made us aware of things to look out for, signs that someone might be deteriorating, also how to reassure the patient. But for me, personally, it has made me realise how to support the family, sometimes it will be like "my mum is going round the bend", and I will say "no, your mum has delirium".*

A particular finding, when describing the additional training needs of staff, was the perceived need to provide additional support to internationally trained staff when supporting patients with DSD. Staff from countries, where family provided personal care and the prevalence of dementia was lower than the UK, meant they were thought to have less familiarity with symptoms and situations not encountered during their training. The following quote provided by an internationally trained nurse suggests that there is less awareness of how to care for people with dementia because, even when people are admitted to hospital, family members provide care:

> HCP9 "*Culture is very relevant, they say older people are being cared for at home by families, they say there are no patients with dementia in India (smiles), they see it as part of the ageing process, or growing old, that's a word they use, they don't see it as a disease itself. So, when they come here, they struggle with the communication and how to care for them. We try to help them work through it on Preceptorship".*

In the study hospital, over 76% of registered nurses are internationally trained, the above quote illustrates the complexities they face in supporting people with dementia.

> HCP9 *"Some of the nurses have explained, dementia has a stigma, it's witchcraft, something nobody talks about, it's seen as shame to the family*".

The hospital staff observed were often meeting patients at the most advanced stages of dementia, compounded with delirium. During the observations however, it was not apparent that qualified staff from overseas were more or less likely to engage with people with DSD than other staff groups, therefore recognising that there is a dissonance between what was observed and what people appear to think.

Participants' accounts often focused on examples of what could work well in individual patient encounters. They would use examples of when access to education and training had or could have made a difference. Participants did also identify how a ward culture could have an impact on the overall care of people with DSD. They did differentiate though between certain wards/units as having more understanding of patients with dementia and delirium with care delivered within other areas that provided care for patients with DSD. The role of the senior practitioner and how the team worked together were highlighted as important.

> HCP1 *"The manager had high standards, she worked on the shop floor, and you wouldn't have found her in the office. She ensured people went on training and she treated all the patients with compassion, and she expected this from her staff too".*

When describing one unit in comparison to others, it was clear this culture extended to the multidisciplinary team with relevant skills and a desire to work with people with DSD. In these units, it was recognised staff held common values and goals and meaningful work.

> HCP2 *"I think it's good because you have a lot of staff on there, you have patients with dementia and delirium and both, but the staff have special skills on there, they have a set routine*."

When asked what makes a difference to the care within this unit, the participant described staff as motivated to work with patients with DSD and opportunities for peer learning. The account in this quote stresses the positive encounters with patients and key staff anticipating their needs:

> HCP2 *"I think people work there because they want to work there. There's a couple of staff who are fantastic, they are exceptional, they are calm, they are friendly, one particular member of staff whom I'm thinking of is very chatty to the patients. I think she reads the situation, I've learned a lot from her to be honest, she really is lovely, the patients love her, she just makes friends with them".*

The observation work on this ward reinforced this view noticing that additional therapy staff were available to patients. While not all their interventions were DSD specific, their ethos was to promote independence and reduce the risk of deconditioning with the aim for a prompt discharge for patients. While the study did not capture interview data from therapy staff, the observation work identified an important point about proactive care addressing wider needs that also reduced and managed the risk of DSD.

When describing the impact of education and role modelling on this ward, the quote below illustrates how emphasising core values such as empathy affected this nurse's approach:

> HCP1 *"I always think about …., about the importance of kindness, trying to imagine how someone with dementia is feeling, and how you approach them and talk to them makes such a difference, it will stop them getting distressed, it does work, I've seen it ".*

Knowing a patient as a person was considered instrumental to implement person-centred fundamentals of care. There were multiple examples in the interviews, how staff on this unit associated maintaining dignity with interacting with patients as fellow human beings and establishing trusting relationships with both the patient and their family.

> HCP1 *"We had a lady with dementia and delirium on the ward; she went on to be end of life. She had a baby Jamie (doll), the family wanted the baby to stay with her throughout the whole time she was there, when she died, they wanted baby Jamie to go to the mortuary. Baby Jamie went along to the mortuary with a little note explaining that when the family come to view their mum the baby Jamie had to be there. The mortuary staff were really happy with that, and the family were really content with that. Right from the start, when she came in from the care home, if she needed a cannula, baby Jamie had one, if she needed oxygen, he had that too, if she got fed, the doll had to be fed…it was her baby".*

As the staff member above conveyed, attempting to understand a person's reality and provide an opportunity to support this, establishing trusting relationship's with both the patient and their family even after the patient's death. While these interventions provided excellent person-centred dementia care, they also supported the patient who had a delirium superimposed on dementia.

Understanding a person's reality is also shared with family modelling how to respond to the person's concerns. This is reflected in the quote below:

> HCP1 *"Sometimes they will say, oh there's a cat on my bed, get it off my bed, you just have to go along with it, the relative will say don't be silly there's nothing there, and I will say, no don't say that, say don't worry I will get rid of it*".

The ability to truly know the patient with dementia in a hospital setting can be seen as challenging for some staff. The 'This is Me' booklet, developed by Alzheimer's Society, aims to help health and social care professionals better understand who the person really is, which can help them deliver care that is tailored to the person's needs. The quote below illustrated how this resource can be used and the knowledge gained from this helped reduce distress for the person with DSD and their family carer.

> HCP3 *"I've been supporting a man with dementia and delirium, he has a good sense of humour, and he likes music. He had the book filled in (This is Me), his son filled it out and so there was quite a lot of information, he used to be a welder, sometimes he spoke about work. I found out his son had a dog; it used to visit in the care home. He really enjoyed the Pets as Therapy visit the other day".*

The importance of knowing the person behind the dementia and using resources to appreciate the relationship between staff and family carers and the positive impact this has on the well-being of the person with DSD was described by staff when talking to family carers. Being able to do this also gave the staff member job satisfaction, in contrast to earlier accounts of participants not feeling able to address patients with DSD obvious needs.

> HCP1 *"She (family member) made sure we understood what her dad was like before he came into hospital, it was important for her that we knew he was mobile, lived alone and could eat and drink independently. She hated if the kitchen staff gave him a beaker, this is where the 'This is me' really helped. I try to imagine what it must be like to be in the person's shoes, if that was me or my family member, I just love my job".*

Interviews with participants working on this ward demonstrated that it was not just qualified staff who recognised the importance of involving and supporting the family carer and their right to be involved in their family members. The above quote demonstrates the variability and understanding of the importance of patients with dementia having a family carer to support them within the wider hospital (this has since been addressed with the introduction of the carer passport).

> HCP1 *"Visiting frustrates me a lot. They are still trying to do that booking for only 1 hour a day, and visiting should only come if it is necessary, when we know that's not how it is. Someone with dementia and delirium should have open visiting, and it shouldn't be restricted to a 1-hour time scale. They should be able to come and go as they please, they are still saying it should only be one person who visits, but that's not quite how it is so with the visiting I really do get annoyed and frustrated."*

Interviews had highlighted the need for education and training and a supportive ward culture with staff who valued their work with people with dementia. There were also examples of staff (often unqualified) whose aptitude for working with patients with dementia and delirium and the skills staff made a difference. What they seemingly unprompted brought to this role demonstrated the value of being alongside the person, and the importance of both recognising and validating good practice. The following is from a quote from the interview data, demonstrating that staff noticed how colleagues worked and their commitment:

> HCP2 *"The best care is 1-1, a lovely example of a HCSW with a patient wandering with dementia, she had so much patience, and although she had assisted this patient and walked along there many times, she did it again and again, she had so much understanding".*

There were however challenges around communication of best practice and shared learning of what supported the person with DSD. The ward handovers and staff sharing information and how this impacted on what the care staff were able to deliver. This quote demonstrates a missed opportunity for team working and sharing information about the patient's condition, particularly if there have been any sudden changes, a key trigger for identifying delirium:

> HCP1 *"Communication is not always very good, they have a lunch time huddle, where they have the ward meeting, we are not told if the patient is going, or they have something newly wrong with them, we don't know what the plan is and sometimes the family asks us and I have to say I will go and get a nurse. But if we had handover, then we could talk about the plan and still get a nurse if needed".*

Opportunities for staff to learn from and apply other approaches designed to support people living with advanced dementia was identified as offering transferable benefits when supporting people with DSD. Namaste Care (Simard & Volicer, 2010) was an example cited as helpful by staff who had received training. Namaste is a gentle, sensory based approach which aims to enhance quality of life particularly in the advanced stages of dementia, when communication became difficult and they were unable to participate in everyday activities. Key attributes of Namaste convey a relationship centred approach, tailoring activities, attending to nutrition and hydration, thus studies have shown to reduce the risk of falls, increase hydration and reduce the use of antipsychotic medications (Bunn et al., 2018). Staff who had attended the training in external settings saw this more holistic approach to dementia care supported patients with DSD and appreciated the positive impact it made.

> HCP1 *"Our training has helped, particularly the Namaste Care training we had recently".*

The following quote illustrates that, when staff have been provided with the knowledge of different techniques, it provided an opportunity and resource to deliver care that is holistic and person-centred and introduced a range of strategies not previously used.

> HCP3 "*I went on the hospice training recently, it was a workshop, it helps you to understand how to communicate with people with severe dementia, for those patients who don't communicate, it has given me some useful tips of things I can do …… It talks about using the five senses, like the music is good, sense of smell, different smells, candles, taste, like food, all those sorts of things really help, it really does help the patient, especially music"*.

However, participants very quickly moved from talking about people with DSD to more generic accounts of person-centred care and approaches that work for people with dementia. Therefore, the data appears to be identifying that some staff did not really differentiate between delirium and dementia and the specific interventions that could mitigate the risk of DSD.

As presented earlier in the chapter, the value of therapeutic spaces for people with dementia were identified by several staff. The following quote demonstrates how one ward had adapted their quiet room into a space where Namaste can be delivered; staff also suggested it is possible to deliver this at the bedside. Creativity of one ward with dementia champions, who are passionate about Namaste Care, was seen as demonstrating the positive impact for the whole organisation.

> HCP1 *"We have a sensory room, it has a fish tank, a bubble lamp, a music system and we have a CD player. We take patients in there, or we can take the equipment to their bay. At the moment we have a bay of 4 and, at night, we take the bubble lamp in every evening because it creates a calm environment to settle them".*

Celebrating care practices like this that work well, using the appreciative focused format of the interviews, seemed to help staff recognise despite the sheer volume of work there was a lot to be proud of. Appreciating and building on these acts of kindness, compassion and empathy, and structured approaches such as Namaste, when supporting patients with DSD, are a key consideration when planning a model of care for this patient group.

> HCP3 *"It has been good to talk about this, it has reminded me of all the good things we try to do, that's really important".*

While these ways of working and engaging were evident in many data extracts presented earlier within the findings chapter, staff were not necessarily conscious of and deliberate about this way of working when supporting patients with DSD.

Post pandemic barriers and workforce challenges

Data collection and what staff and family discussed was affected by their experiences of COVID-19 and the challenges and restrictions experienced. Specifically, they highlighted ward realignment, infection control and rules, and the interpretation of rules around visiting has impacted on their ability to provide continuity of care, person-centred care, the orientation of people with dementia and the staff with the skills and expertise to care for them. The utilisation of space, ward realignment and redeployment of staff was a challenge during 2020/21, appreciating what was considered to work well in this difficult time was described.

> HCP1 "*There was an end-of-life care ward for COVID-19, and a lot of staff say that was really good in there, they were able to have the time and space especially for patients with DSD who were very distressed. They had a lovely team, staff from all different areas but with a good manager. Some families that had been on there have come back in with a different family member and they have given really good feedback".*

There were however more accounts of how the pandemic had a detrimental and ongoing effect on staff and how care was organised. One staff member during non-participant observations described the following feelings of anxiety, about both the staff and the care patients received.

> *"I'm worried about the ward, I worry about my colleagues, and we can't provide the care we want to, and I worry about the patients, they won't get the care they need, I care from my heart, I'm so proud to do this job"* (Field notes/HCP).

The emotional impact of caring resonated with a previous interaction during non-participant observation, highlighting the importance of this additional data collection phase. The researcher went back to see the nurse after data collection completed to check on her well-being.

One family carer explained how visiting restrictions affected her dad:

> FC3 *"That really was the nail in the coffin for my dad because he couldn't see people, he couldn't go out, we had a rota of people calling on him, other people would call in on him and check on him, but we progressively saw the decline in the dementia then".*

On the organisation of ward, space had also been directly impacted by COVID-19 restrictions. Family carers' concerns over isolation were also reflected in the non-participant phase of data collection. They expressed the concern over their family member becoming deconditioned, could not seek help if they needed the toilet, didn't know how to use the call bell and the sound barrier was very noticeable.

> HCP1 *"On the wards that were cleaned and refurbished during the pandemic, they have divided the 16 bedded end into 4 bays of 4 each divided by a sliding door"*.

> HCP2 *"I know that some families have raised concerns, they feel their family member is isolated. I know that sometimes the patient may call out and not be heard. I guess some patients with dementia and delirium may find it peaceful".*

These comments above support the findings from the non-participant observations.

The role of family and carers and their rights to be involved in the care of their family member has received significant attention post pandemic, for example awareness campaigns such as "John's Campaign". Staff appreciated the positive impact open visiting could have but discussed the challenges they still face when advocating for this.

> HCP 5 *"Someone with dementia and delirium should have open visiting, and it shouldn't be restricted to a 1-hour time scale. They should be able to come and go as they please, they are still saying it should only be one person that visits, but that's not quite how it is so with the visiting I really do get annoyed and frustrated."*

Appreciating the benefits of supporting family carers to be present with patients with DSD and the interpretation of the visiting policy was not without its difficulties, staff discussed other positive initiative's that have been developed

> HCP1 "*There's a carer's passport coming into place that will really help a lot. They are going to have a lanyard to say they are a family carer throughout the hospital stay".*

Practitioner working with family members to support interventions for the person with DSD

The review had found that there was potential for family members to work with nursing staff to support people with DSD but limited evidence of how this was achieved or how it benefited the person with DSD. Practitioner interventions are considered here in respect of approaches involving family carers, additional therapeutic interventions or activities that were used to support patients with DSD.

Family carer’s knowledge of the person’s baseline cognitive status was helpful in detecting acute cognitive changes indicating delirium in the older person. This knowledge and willingness to complement the care provided by staff helped staff who felt overstretched and often resulted in the older person receiving fundamental care as the following quote illustrates:

> HCP1 *“We had a man who had a lot of falls, his daughter came in every day (every afternoon for a couple of hours), she stopped him attempting to climb out to the bed, he would sit on the bed, transfer to the chair for her, and then he would get back into bed, so that helped him, because if she hadn’t been there he would have been all over the place”.*

Family caregivers participated in strategies to manage DSD by encouraging recovery-oriented activities. For example, family caregivers engaged their relative in exercise and cognitively stimulating activities.

> HCP1 *“some of the visitors, they are quite happy to take their mum for a walk if they are mobile, they can walk them out to the bathroom, so they are not being incontinent, so they can go more frequently to the toilet”.*

During the non-participant phase of data collection, family carers were observed to support their relatives to engage with music; playing music at the bedside, including faith based and culturally specific music. They were observed to interact positively with other patients on the ward who had DSD, which provided comfort and reassurance. Some family carers assisted staff in providing help with personal care, assisted at mealtimes, providing close observation/support and helped to complete the “This is me” information. There were many observed instances of when family carers were a channel of communication, updating the ward teams on their relative’s history, social circumstances and usual abilities.

During the hospitalisation, some family caregivers detected changes in the older person's cognitive status, indicating delirium, and described how by watching nursing staff anticipate their family members’ needs this led to some positive interventions. This quote demonstrates the potential for reciprocal learning and support between nurses and patients, where family members learned new ways of communicating and acting with their family member:

> HCP10 *"My mother-in-law has advanced vascular dementia, she's been in the hospital now twice in the last 6 months, she has also had delirium. I used to try to imagine what it was like intellectually, now I've gotten to see what it is really like. A nurse was with her yesterday, she introduced herself, she built up a rapport, she explained things before giving the injection, it could have been a stressful thing, but she made it a very calm experience. I then thought, I want to be like this nurse".*

As noted earlier, family caregivers were instrumental in identifying cognitive and behavioural changes in their family members. When staff valued that information, family caregivers recognised how it made a difference to the overall care received.

> HCP1 *"She also made sure we understood how he was before he came into hospital, it was important for her that we knew that her dad was normally mobile, lived alone and could eat and drink independently. She hated it if the kitchen staff gave him a beaker. The is where "This is me" really helped".*

As illustrated in the following quote, staff accepted that family carers can help with DSD management by engaging the older person in familiar activities. Family caregivers knew which activities were preferred due to their intimate knowledge of the older person. There were examples of where family carers advocated for meaningful activities to provide company and interaction.

> HCP10 *"I went to the nurse's station, and I said, I know it's late and its bank holiday, but could we order that TV for her, that special one with all the old stuff on it, I couldn't think of the name, the staff immediately knew what I was talking about (RITA-Reminiscence Interactive Therapy Activity".*

Staff also felt proud when they were able to provide support.

> HCP1 *"Kinda makes you feel proud, is when a patient's family member has said delirium, and I've said, have they talked to you about this, do you know what this means?".*

Additional ward-based activities that supported patients with DSD included Pets as Therapy visits and musical memories. Pets as Therapy (PAT) is a national charity that enhances the well-being of people through visits provided by volunteers with temperament assessed dogs/cats, who visit care homes, hospitals, hospices, etc.

Summary of key findings from the Discovery and Dream Phase

The key findings in this chapter related to, relationship centred care and supportive interventions for patients with DSD, and the AI process. The Discovery and Dream phase of the 4D cycle revealed that, in hospital, the care of patients with DSD for both family carers and staff was a complex area of care, and the complexity between understanding both dementia and delirium required a relationship centred approach to care. To summarise:

- The non-participant discovery phase had some parallel learning.
- Almost everyone living with dementia and communication difficulties were able to participate in the AI process in some way.
- The majority of dream ideas discussed at interview focused on a patient focused outcome with the remainder focusing on the need for more education.
- Understanding of DSD is complex and exposure to patients living with dementia with delirium superimposed is variable across the Registered Nursing workforce.
- Those positive moments of person-centred care were often driven by unit champions.
- Family carers were often a very underused, underrepresented source of support for staff but often had good insight into what works well for patients with DSD.
- Huge challenges around the environment and how noticing distress and responding helpfully influenced patient care and outcomes.

Since completing this work, ideas discussed in the Discover and Dream phase are influencing the Dementia and Delirium clinical strategy and ongoing projects around the environment and therapeutic spaces are continuing this work.

Chapter 6 – Discussion, recommendations and conclusions

Introduction

This study completed a scoping review of the evidence and used a multi method approach framed with an Appreciative Inquiry (AI) lens to understand how supportive interventions involving family carers and staff caring for patients with DSD in hospital could improve the experience of care. Specifically, the study sought to understand:

- What is the evidence that supportive interventions that involve patients with delirium superimposed on dementia (DSD), family carers and healthcare professionals lead to improved outcomes for the patient and experience for the carer?
- How do hospital staff involve family carers in recognising the signs and symptoms of delirium and providing effective caring for someone with delirium superimposed on dementia?
- What are the experience and perspectives of the family carers who are caring for a patient in hospital with delirium superimposed on dementia?
- If a relationship-centred approach to dementia and delirium care can be co-designed and provided by staff and family carers of patients in hospital with dementia and delirium.

In this chapter, I discuss the extent to which the key findings from the study answer the research questions. I consider the following while drawing together both phases of the study:

- The challenges staff and others experience differentiating symptoms and presentation of dementia from delirium superimposed on dementia
- Professional insights/recognition of the issues and unqualified staff observations; and how different sources of knowledge are valued and inform care impact on family and their ability to differentiate between dementia and delirium

- Environments of care that support or hinder the recognition and reduction of DSD
- How insight from multiple sources can inform handover and continuity of care
- The unique role of HCSW in supporting patients with DSD
- The impact of relational communication in dementia and delirium care

I will report and reflect on strengths and limitations of using an appreciative approach in answering questions about supportive interventions for patients with DSD. Reflections on lessons learned include the impact of my role as a clinician/nurse researcher and a novice researcher on the AI process. The chapter concludes with contributions to knowledge, and implications for practice and future research.

Overview of the findings

The scoping review (Ashton-Gough et al., 2025) included 15 studies exploring, or relevant to, the care of patients with delirium superimposed on dementia involving family members or their proxies working with nursing staff in hospital, reported in chapter 2; this found relatively few published qualitative studies. Many of the included studies did not discuss the interplay between dementia and delirium involving family carers in depth or focused on patients with dementia. The review found that there was recognition of the importance of the family, or their proxy, as a way of supporting staff when providing care to people living with dementia with delirium, although only two studies considered the quality or mutuality of the patient-family-carer relationship, or how confident family felt to raise concerns (Boltz et al., 2015, Kang et al., 2017). This informed the rationale for the next phase of the study in wanting to understand how relationship centred dementia and delirium care could be achieved for patients with dementia and their families.

The relational constructionism framework, using an appreciative inquiry approach to data collection, enabled me to explore how strategies likely to promote working relationships between hospital staff, family carers and people with dementia can avoid or reduce the impact of delirium.

Following the 4D cycle of AI; using an appreciative approach, non-participant observations and interviews using a story telling approach which were supported using emotional touch points. This enabled the study to identify what was currently working well/perceived examples of good care and areas that they identified needed additional support. Thirteen people were interviewed which consisted of 3 Registered Nurses, 1 doctor (also a family carer), 4 healthcare support workers (HCSW), of which one was also a family carer, 2 chaplains and 3 family carers. Additionally, seventy-four patients were observed with delirium superimposed on dementia over 11 different time periods, and across 8 different ward environments.

The findings demonstrated that, as a process, AI was acceptable to all groups of participants. The non-participant observation phase provided the context to understand the family carer role, how patients with DSD were being noticed and cared for, and to pick up those examples of good care that may have been overlooked in the interview phase. Staff appreciated the time and space to share experiences and to discuss aspects of care that could be improved, and the opportunity to share good practice. It encouraged participants to consider what actions may reduce distress even when the observational data and examples were often of where care had fallen short. Family carers did not respond solely as study participants. They appreciated the 1-1 support and time during the interview stage as an opportunity for them, not only to share their experience, but to talk openly about their caring role and the emotions connected with this. It provided an opportunity to learn about their experiences of delirium and disclose their coping mechanisms. As a researcher with clinical experience in the field being studied, it was possible to understand what was being shared and how to consider what support could be offered after the interview had ended. It felt that I had a professional responsibility to do this alongside my role as a researcher. Having personal experience of delirium, alongside professional knowledge, added strength in really appreciating how family carers felt.

Discovery Phase

The findings resonate with previous research, (Kang et al., 2017, Julian et al., 2022, Moore & Denning, 2020), in that they highlight there is a need for education for family carers and nursing staff. Family carers were distressed to see family members hospitalised with delirium, but when family carers were informed and involved, the care of the patient with DSD was improved. These findings add to what is already known about DSD in hospital, by demonstrating how opportunities and interactions between staff, family and people with DSD can improve the in-patient experience.

Hospital staff face unique challenges when providing person-centred care (PCC) for patients with dementia. Some key experiences and insights include the environment, unfamiliar surroundings which can be overwhelming and heighten confusion and agitation. Implementing Person Centred Care is universally understood as an approach to care that involves understanding everyone's needs and preferences, and time is often considered a factor. Nurses however, often expressed the need for enhanced training and education to understand the complexities of the emotional and psychological challenges they were facing. The observational data demonstrated the challenges and opportunities staff encountered. There were similarities with study findings looking solely at supporting people with dementia in hospital, exploring areas such as resistance to care, identifying how ward cultures and routines influenced care delivery and took priority influencing the ability to deliver person centred care. Featherstone et al., (2019) and Handley et al., (2019) identified how organisational priorities such as patient safety need to make explicit links to person-centred care to reframe these organisational concerns as opportunities to provide person centred care. There is evidence about the difficulties nurses experience in delivering PCC in hospital and the importance of ward cultures that prioritise dementia care and institutional support that actively seeks to raise the profile of dementia care (Abbott et al., 2022). Brossard Saxell et al., (2021) identified care received by inpatients with dementia was dependant on individual registered nurses' knowledge, personal aptitude and the ability to compensate for structural flaws, suggesting minimising arbitrary outcomes of care for patients with dementia, consistent organisational support in the form of educational interventions and the allocation of resources is crucial.

How familiar practitioners were with caring for people with dementia appeared to be affected by training and prior personal experience of someone with DSD. However, from the observation data, this was unproven. Kindness and attempts to communicate and reduce anxiety were witnessed. On reflection, interpreting whether the approach used by the staff was based solely on their understanding of dementia or incorporated additional skills of providing person centred care in managing delirium on a background of dementia was complex. Data provided from the interviews came from staff that had trained overseas, and from the UK. Some participants suggested this applied to nurses from countries where the incidence of people with dementia was considered much lower than the UK, and family would assume main care responsibilities for older people. Brooke et al., (2018), in a systematic review and meta synthesis, found limited evidence of the impact of healthcare professionals' and care workers' culture in relation to their provision of person-centred dementia care, suggesting this was an under researched topic. They stressed the need for investment in the acculturation of migrant healthcare workers to the culture of the host country, workplace, and support with communication as fundamental to the provision of person-centred dementia care.

The additional impact of DSD raised questions about how staff recognised and responded to patients with behavioural and psychosocial presentations that were not solely due to dementia. In these situations of staff ignorance, the ability of family carers to differentiate between the two was an important resource for care, especially when family recognised what was happening, and likely triggers. However, they also needed reassurance about the sudden and distressing changes in their relative's behaviours. The findings demonstrated how person-centred care should be extended to addressing the presence of family carers both as a source of information and a group needing to be supported to understand relatives' behaviours.

Understanding the current context for the care of patients with DSD in hospital

The term delirium lacks specificity and was too often conflated with dementia symptoms and this affected how staff responded in the study. This was particularly noticeable during the discovery phase when embedding myself in everyday practice, when asked about patients with DSD reported numbers did not reflect the numbers, I observed during the non-participant observation phase. Staff understanding was variable dependant often on the ward setting and seniority of staff I spoke to. The term is usually assumed to be an acute, fluctuating, transient and reversible condition caused by physical illness (Cloak et al., 2024). Once the acute episode has improved, the premorbid level of functioning is reached again, with personality reappearing intact. However, research (Avelino-Silva et al., 2017, Morandi & Bellelli, 2020, and

Nitchingham & Caplan, 2021) shows delirium is often irreversible, especially in older people and those with pre-existing dementia.

The review, observation and interview findings demonstrated that hospital staff and family carers did not always recognise or consider the possibility of delirium occurring in a person with pre-existing dementia. Conceptually, it may be more useful for DSD to be considered an “acute exacerbation” of dementia, precipitated by a harmful insult akin to an acute exacerbation of heart failure or acute on chronic renal failure. However, there are no established biomarkers for delirium, so DSD is diagnosed and monitored clinically (Nitchingham and Caplan, 2021).

It was a consistent finding of the study, how poorly understood DSD was by family carers and healthcare professionals, and indeed the public. The focus was often on situations that might expose patients or others to risk. This preoccupation led to a reactive approach to assessment of people with dementia and the possible presence of delirium. However, the non-participant observation phase highlighted how staffs’ experiential learning was observed to make a difference. During interviews, the HCP who were more alert to the possibility of DSD, were the participants that had the most contact with the patients and were still involved in providing fundamental care. From the observation data, a nursing qualification did not appear to be key to recognising the symptoms of delirium and how to mitigate their impact.

Some HCSW, however, spoke of how the training they had completed had made a difference and the importance of learning from others. There were some examples of good role modelling and picking up tips and identifying staff who were demonstrably kind and understanding. What was observed and spoken of was the varied ability to form connections and relationships with family carers. There were individual examples observed during the non-participant observation phase, despite potential barriers to communication such as English not the first language for the staff and symptoms of BPSD alongside DSD for the patient. There were observed attempts of kindness and a willingness to be compassionate rather than solely task focused. Shared examples during interviews provided examples of the impact of a good role model, one that led by example, worked alongside their staff and expected a high standard of care and care that was compassionate. While other studies have stressed the importance of senior endorsement for the delivery of person-centred care in hospitals (Handley et al., 2017, 2019); these findings suggest opportunities to recognise good practice and peer to peer learning were also important.

A meta-ethnography, (Bridges et al., 2012) explored the evidence of the impact of nurse-patient relationships on patient care and outcomes, several of the primary studies reported on the emotional impact of the nurse within the nurse/patient relationship. Bridges identified while nurses aspire to develop therapeutic relationships with patients, the organisational setting is strongly associated with the ability to form these relationships. In some settings, such as critical care, where one to one care is common, this provided a better opportunity than others. Nurses working on general wards were more likely to encounter moral distress. During this study, staff providing good examples of relationship centred care for patients with DSD were working on older people's wards including frailty units; there was the potential for the speciality of the ward to drive forward the culture of care. However, approaches to care were often variable and rather than the speciality focuses of the ward, it was the HCP who had a deeper understanding of dementia care, and who were able to focus on the fundamental aspects of care, and family carers recognised this, and this in turn achieved a positive outcome and a more lasting patient and carer experience. As with the HCSW, it was their experiences of care and needing to seek out information themselves that was seen as shaping their responses. Sadly, however, they reported that they often felt unheard.

Complexity around differentiating symptoms and presentation of dementia from delirium superimposed on dementia

The findings demonstrate that caring for someone with DSD is a stressful and often overwhelming experience for both staff and family carers. While delirium and dementia have similar cognitive and behavioural symptoms, previous dementia caregiving experience does not necessarily mitigate distress associated with DSD, a finding congruent with previous research (Fong et al., 2019, Julian et al., 2022).

Changes in behaviour for the person with dementia was often interpreted as bad behaviour as a symptom of dementia. The relationship between DSD, and behavioural and psychological symptoms of dementia (BPSD), may be interlinked but is often disregarded. When considering language paradigms, the term BPSD first arose in 1996 (Cunningham et al., 2019). There was clearly still some confusion around these terms even though the use of BPSD is increasingly discouraged, staff did not have alternatives to explain to each other or families what was happening. Family perspectives on the language of behaviour have not been fully explored in emerging studies, following the campaign to ban words like BPSD. Wolverson et al., (2022), identified family carers most preferred term, was a new concept “Behavioural and Emotional Expressions of Need”, few people in this study had heard of this. The Wolverson study found that carers’ preferred language was positively construed, easily understood and heavily focused on the person-centred terms that attributed behaviour to unmet needs.

Engaging participants in talking directly in terms of DSD was insightful and challenging for myself. Some participants did not appear to understand these terms or quickly went back to talking about person-centred dementia care rather than exploring other alternative interpretations, which could lead to solutions and reduce the risk of known negative outcomes. Incorporating this language within Tier 2 Dementia Training is established and embedded within individualised care plans, a whole system approach to cultural change needs to be adopted.

Professional knowledge, moral intuitiveness and cultural influences

Nurses’ knowledge, attitudes and perceptions towards people with dementia and the culture of care on the wards affect staff responses to DSD and what is prioritised. It has been suggested that care for dementia patients is affected by social attitudes and perceptions about the illness (Dove et al., 2016, Gerritsen et al., 2018, Yaghmour et al., 2022). In 2019, authors reported that nursing students have almost no knowledge about how to provide ideal care to patients with dementia and struggle in dealing with the behavioural problems of patients (Strøm et al., 2019). This study demonstrated it is important to distinguish between nursing knowledge, attitudes and perceptions when considering the knowledge and skills of nurses. During the non-participant observation phase, there were few examples of interactions between patients with

DSD and nurses. Student nurses appeared to focus on the practical, task focused aspects of care and appeared uncertain of how to respond to DSD. The interviews identified that there was concern over the lack of dementia and delirium education built into nursing, and medical curricula suggesting little is taught about DSD. Some participants, but not all, appreciated how little they knew about the topic.

Several authors have identified the interplay between knowledge, attitude and perception in how nurses respond to patients. Knowledge refers to cognitive expertise gained through learning, emphasising the knowledge base of nursing practice (Hatamleh & Sorio, 2017). A nurse's attitudes are their personal belief system which may differ from broader societal beliefs or norms and can differ across cultures and countries (Coban et al., 2015; Yaghmour, 2022). Their views, or perceptions, relate to how they and others may interpret situations or actions in their profession. Each of these concept's knowledge, attitude and perception affected how the participants with prior experiences of caring for people with DSD had the biggest effect rather than formal training.

The findings from this study found that nurses' variable knowledge was dependant on the ward environment, personal experience, ward priorities, perception of cultural influences, leadership, attitudes and perception and influenced how participants recognised the needs of patients with DSD. It was not just about education.

The non-participant observation phase of the data collection found that HCSW appeared to have a greater insight into the complexity of DSD than their nurse counterparts. They were able to identify this as very different from dementia alone, had the confidence to talk to family carers about delirium and were often expected to/asked to update families about the patient's condition. They also provided reassurance, and some even provided educational materials. Other work exploring HCSW interactions with people with dementia similarly illuminated areas of compassionate, person-centred practice (Schneider, 2010). Schneider's work identified how HCSW took overall responsibility for the ward, made a distinctive contribution to the care received by patients with dementia but they often felt undervalued. Their role at the bedside was the source of their authority, supporting patients with DSD, their cohesiveness as a staff group and their interactions with members of the MDT and the potential role in educating and reassuring families were considered of key importance. This suggests the framework of relationship-centred care may help to understand the role of HCSW more than a focus on individual encounters when providing person-centred care. This study heard similar concerns within the interviews from HCSW of feeling undervalued. The appreciative lens however emphasised the learning from examples of kindness, compassion, going that extra mile and relationships with family carers which, in some situations, appeared to go beyond their role.

Impact of nursing migration and how that affects care priorities and cross team working

Due to current trends in global migration and recruitment approaches, healthcare in the UK is delivered by a culturally diverse workforce. In the period 1990/1991 to 2021/2022, the percentage of new Internationally Educated Nurses (IEN), Nursing and Midwifery Council (NMC) registrants rose from 10% to 53% of the total annual number. In 2022/2023, more than 40% of new NMC registrants were trained outside the UK, which is the highest in two decades (Buchan & Catton, 2023). Consequently, there is a need to appreciate healthcare professionals' and care workers' cultural backgrounds, and if that has an impact on how they recognise symptoms of dementia. Brooke et al., (2018) discuss a lack of clarity regarding the intersection of culture in the provision of person-centred dementia care. In the study site, 76% of the nursing workforce were internationally trained. Of the three RNs interviewed, two were internationally trained and one of the two chaplains had trained in a country other than the UK.

From the 12 periods of observation undertaken, approximately 65% were internationally trained considering key staff members observed.

The impact of how much experience staff had of working with older people, their understanding of dementia was highlighted throughout the interviews. Some participants acknowledged it was not an aspect of nursing work they had received training in, or experienced, as the patient population in their home country was younger.

Participants described their appreciation of the challenges overseas nurses faced when arriving in the UK and their often-short period of induction that provided minimal mandatory training on dementia care.

During both phases of the AI, both healthcare workers and family carers referenced attitudes of agency staff who considered distressed reactions as patients being difficult or behaving badly. It is possible that staff with intermittent contact with patients with dementia were not equipped to understand that preventative intervention, early diagnosis and certain treatments for some dementia syndromes are available (Brooke et al., 2017). The research findings of this study observed multiple opportunities for learning from everyday practice, from knowledgeable and experienced role models and from providing fundamental care. The pressure for qualified nurses however, often felt the focus was on achieving targets such as reducing the risk of inpatient falls and hospital acquired pressure injury, completing paperwork and drug administration rounds.

Nurses are the dominant workforce across hospital settings, therefore it is essential for nurses to be culturally competent; this includes an understanding of how culture impacts on their own, as well as their colleagues, patients with dementia and delirium and the family carer’s beliefs and values regarding this area of care. Being culturally competent was highlighted by the participants within this study when considering the Dream phase of AI. An overseas trained nurse now supporting staff education believed that overseas nurses required a longer period of support, which may include the preceptorship programme, but it was felt dementia education and learning needs to be delivered regularly and revisited and not just accessed at the start of the employment to address the lack of exposure to dementia care before.

Design and delivery of formal dementia education and training

“*The most effective training programmes combine a range of methods appropriate to what is being taught so that theory, practical application, and reflection on and consolidation of learning can take place”.* (Surr et al., 2023, pg.19)

There is an abundance of research and guidance on different methods of learning about how to support people with dementia and findings from this study show that education and training was important by various participants who highlighted areas such as learning by simulation techniques and the need for an extended preceptorship programme. The simulation scenarios are based on real patient situations and have been used to share the learning. While the person living with dementia may not have been directly involved this has instrumented a more powerful impact in their delivery and have been used when providing duty of candour to relatives when feeding back in response to learning from incidents. However, findings from this study found varied evidence of this being used in ward-based learning, curricula and post qualification training. While training in Dementia at Tier 1 was mandatory for this organisation, Tier 2 was suggested as essential for those with regular contact with people living with dementia making uptake more difficult.

There are several important examples of training programmes that have been developed with the direct involvement of people with dementia.

Involving people living with dementia, often known as experts-by-experience (EBEs), in the design and delivery of dementia training is a relatively new concept. Students, lecturers and EBEs value the input of EBEs to the education of healthcare professionals, and EBE involvement is well established in mental health nursing (Horgan et al., 2020; Scammell et al., 2016) and social work education (Goosen and Austin, 2017). Within Learning Disability, the introduction of The Oliver McGowan Mandatory training on Learning Disability and Autism is a vehicle for culture change and its aim is expected to improve the health inequalities experienced by people with a learning disability and autistic people, increasing the knowledge and improving the attitudes and skills of health and social care staff who treat and support them (National Institute Health Research, 2023).

Involvement of those with dementia in research is more established (Di Lorito et al., 2020; Flavin and Sinclair, 2019; Goeman et al., 2019; Gove et al., 2018; Iliffe et al., 2013). However, evaluation and discussion of direct involvement in training is less well reported, and published examples of that involvement are rare. A suggestion that involvement of people with dementia in training is that as a result of nature of decline, making it more complex than those with other health conditions.

Nonetheless, there is a growing number of creative ways that people with dementia, either directly or indirectly, are being involved in training. The few evaluated and published studies include:

- Programmes offering students time-limited placements with people directly affected by dementia (Banerjee et al., 2017).
- Producing audio or video recordings used across multiple deliveries of a training programme and/or directly including people with dementia in discussion activities during training sessions (Dodds, 2003); and
- Facilitated implementation of learning alongside people living with dementia, using arts- based approaches (Guzman et al., 2017a).

Kingston University have implemented a project aimed at supporting health and social care students to develop their skills and knowledge by supporting people with dementia. The project provides students with volunteering opportunities in the local community, which will benefit them both professionally and personally, as well as supporting those living with dementia and their families and carers. Working in partnership with Kingston Hospital, the local Alzheimer's Society and several care homes, students are facilitated to have learning opportunities where they can spend quality time with someone with dementia, seeing the person and not just their condition. The University of Portsmouth implemented "The Time for Dementia" education programme, designed at Brighton and Sussex Medical School, in partnership with Alzheimer's Society, to develop a new generation of healthcare professionals who are more informed and understanding of dementia. The focus is on fostering compassion and understanding, in comparison to the typical clinical model most often seen within clinical placement and practice. Paramedic Science undergraduates will be paired up and given a unique opportunity to visit a family affected by dementia. Second year students will visit the same home, up to five times over two years, allowing them to learn about the lived experience of dementia within a home environment over an extended duration.

Evidence from published studies indicates that positive exposure to people living with dementia leads to positive outcomes for learners. For example, regular home visits to people with dementia alongside more formal education can facilitate compassion and positive attitudes (Bickford et al., 2019). This leads me to consider how

Compassionate Neighbours projects, such as those often run by Hospices, projects to help reduce loneliness and social isolation amongst people living in the community, who are at the end of their life due to serious illness or old age. The projects buddy up volunteers with individuals in the community, some of whom may be living with dementia, and the Namaste Care project which involves trained Namaste Dementia Care volunteers delivering one-to-one, personalised Namaste Care sessions to a person in their own home (with their carer present), or residential home. While these projects are intended to provide compassionate support and friendship for local residents/patients or people in need, the reciprocity experienced by the volunteer and the formal education and training the volunteer receives also provides outcomes as that experienced by the paramedics and health and social care students.

The published examples demonstrated many reasons why the involvement of people with dementia in education and training is important and provides valuable experience and insights (Banerjee et al., 2017; Dodds, 2023 and Guzman et al., 2017a). This work has influenced my direction and focus in developing education and elements are embedded within the study sites dementia and delirium training delivery, and those also embedded within the author's own training delivery.

Table 32: Examples of ways to include the experiences of those directly affected by dementia in training (Surr et al., 2023)

Direct methods

- People living with dementia, family members, and informal caregivers delivering talks to learners.
- Learners having formal placements or spending time with people directly affected by dementia in service or home settings.
- Co-learning with/from people directly affected by dementia, such as during intergenerational activity or during artistic/creative sessions.

Digital resources

- Video and audio recordings made by or with people directly affected by dementia talking about their own experiences.

Indirect methods

- Poems, books and blogs written by people directly affected by dementia.
- Plays, exhibitions, and other artistic productions and representations of the experiences of people directly affected by dementia.
- Working with groups of people directly affected by dementia to gather stores of their experiences that can be used as case studies and examples within training.

There are a variety of approaches that can be used to deliver or facilitate learning (Surr et al., 2023). It is suggested that a variety of approaches using a combination of methods to suit those with preferred learning styles are best suited to delivery of content. Often a layering approach is the desired style, such as a short talk, or lecture to cover theory or information-based content, an interactive activity or simulation, followed by reflection and discussion.

Surr et al., 2017, carried out a large study in the UK, which explored the elements of impactful training across the health and social care workforce (the "What works study"). This involved:

1. a large review on published research of dementia education and training (Surr, 2017).
2. auditing for the current dementia training against the Dementia Training standards framework for England using a national survey (Smith et al., 2019).
3. surveying staff who have completed dementia training and evaluating the impact of training on theory to practice and its impact on their knowledge and confidence (Parveen et al., 2021).
4. in depth case studies of ten health and social care provider organisations whose training, as shown in the audit, showed evidence of good practice (Sass et al., 2019, Surr et al., 2020, 2019b).

Using data from all the above sources, a set of criteria were established, a training manual and tool has been developed and can be accessed from the study website (Leeds Beckett University, dementia-training-design-and-delivery-audit-tool-manual-v4_0.pdf n. d). While the study was developed in the UK, it is transferable to other high-income countries.

Learning and development in acute hospitals

In the UK, the number of people living with dementia is growing and the number admitted to acute hospitals is likely to increase. Internationally, the way physical and mental health services are structured varies, and the two are often poorly integrated (Triliva et al., 2020). Therefore, the identification of dementia care as “specialist care” maybe unhelpful labelling it as such might unintentionally create barriers to incorporating dementia care into general healthcare services. For example, the prevalence of dementia in acute hospitals suggests the needs of people with dementia often overlap with general medical care. Treating dementia care as a niche area might overlook the necessity of preparing all healthcare staff with the skills to provide person-centred care. While specialist dementia care teams, and roles such as Admiral Nurses, play a crucial role in supporting patients and families with complex needs, there is a growing need for training on a wider level among general hospital staff to address the unique challenges faced by patients living with dementia. Specialist teams can provide advanced support, but general staff must also be empowered to deliver compassionate and effective care. The increasing demand for dementia care highlights the need for systemic changes, such as creating dementia-friendly environments and improving care coordination across hospital departments.

Examples of good practice and recommendations for learning show it is possible to develop skills in dementia and delirium care and these kinds of initiatives, such as a simulation approach to education has been implemented in the study site and is reported to be well evaluated; although findings from this study suggest staff may need more support.

Dementia adds significant complexity alongside the management of chronic and acute physical and mental health conditions. People living with dementia often have poorer outcomes, because of a hospital stay than older adults without dementia in comparison. Being acutely unwell, alongside a change of routine and often the impact of added delirium can provide additional challenges for healthcare staff providing care in a very busy and challenging environment. Hospital staff consistently report they struggle to meet the complex needs of this patient group and highlight how their education both prior to and since entering the profession has not adequately prepared them for this role (Brooke & Ojo, 2018; Gwernan-Jones et al., 2020b).

In the UK, a number of initiatives have encouraged and promoted the provision and uptake of dementia training in acute hospital settings, including the National Institute for Health and Care Excellence (NICE) Dementia Guideline (NCE 2018), which supports all health and care delivery to people with dementia; the Alzheimer's Society "Fix Dementia Care: Hospitals Campaign (Alzheimer's Society, 2016), National Audit of Dementia, Royal College of Psychiatry which called for increased dementia care training, which included annual reporting and a higher level Tier 2 training. It is clear hospital staff need to be supported to access ongoing CPD training.

Face to face delivery methods such as experiential learning and simulation support development of empathy. Development of staff empathy towards people living with dementia has been identified as fundamental in enabling the delivery of person-centred care in hospital environments, alongside understanding and responding to the need to change and adapt when care practices may need to change alongside dementia specific skills that can be applied in practice (Handley et al., 2019). The study site provides a variety of approaches to training such as the Virtual Dementia Tour, Tier 2 Dementia Training based on the E- DEALTS programme, Namaste Care workshops and Dementia and Delirium Simulation. Training has also been accessed, but other hospital sites and the research site has been instrumental in supporting another NHS hospital to set up the Dementia and Delirium Simulation there. What may be unique to the study site is that the training is offered as interprofessional learning, therefore staff learn from each other, acknowledge the difficulties within each other's role and reflection and debriefs provide further learning and evaluations. One of the challenges for the site is that staff have the opportunity to access training, are aware of what opportunities there are and understand how this could enhance their practice. Findings identified that staff enjoyed the training, and it enhanced their practice, but they needed more. Currently training at Tier 1 on trust induction for all new starters is mandatory, but other training opportunities listed above are mandated as essential therefore relying on many factors such as the gift of time, leadership and shift patterns. A recommendation to come from this work would be raising the profile and importance of training in dementia care in line with other areas of care such as the Oliver McGowan training for Learning Disability.

Impact on family and their ability to differentiate between dementia and delirium

Despite family carers' potential role in DSD detection and management, the scoping review established that their experience has not been extensively explored in the literature. It is suggested that family carers can assist in early detection of DSD, owing to their knowledge of the person's baseline cognitive status (Carbone & Gugliucci, 2015; McKenzie & Joy, 2020) and importantly their functional ability. The ability to detect DSD is important before, during, and after hospitalisation as delirium may return. A significant finding from this study identified some family carers who had repeated experiences of DSD knew what to look out for. This experience also led them to have the confidence to speak out to healthcare professionals, particularly around matters like the timing of hospital discharge.

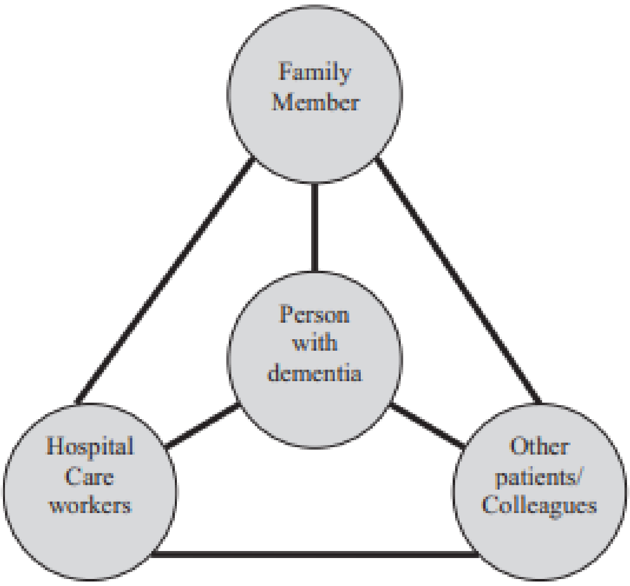
Family carers found DSD to be a difficult and upsetting experience resulting in negative emotions. This finding was reported in Morandi et al., 2015 as distress, anxiety, exhaustion, helplessness and frustration. The family carers reported being unprepared emotionally for seeing their family member change so dramatically. This finding has been identified in various studies (Harrison, Denning and Aldridge, 2021; Morandi et al., 2015, Nitchingham and Caplan, 2021).

Family carers in this study also described their experience of feeling isolated and alone during the pandemic and described the lack of social connectedness to support them. The interviews with family carers found that participants often recognised that delirium when superimposed on dementia was different and crucially distressing to watch and experience the long-term consequences. Very little is discussed in the literature or evidenced in the participant's accounts or observational data of family carers' need for support in dealing with the emotional consequences of witnessing DSD. Others have noted how difficult it is for family carers to support people with behaviours they find challenging (Feast et al., 2020; Kim et al., 2021; Nitchingham and Caplan, 2021; Poon et al., 2022) but this is one of few studies that has considered the impact of DSD. It has also demonstrated the range of ways that family carers, when facilitated by staff, can aid care from helping with personal care to sharing important information.

There was evidence of where relationships could have been improved and some examples of good practice and attempts to build strong relationships. Family carers discussed during interview their experience of a previous delirium episode, how they recognised what they needed to do to avoid future episodes, for example the importance of being discharged in daylight hours. This was not always appreciated by staff and trying to navigate care highlighted a power imbalance, leaving family carers feeling disempowered and believing the healthcare team control over the patient's care did not recognise their role (Feat et al., 2020; Julian et al., 2023; Lindeza et al., 2024; Smith et al., 2022). The study demonstrated good practice and what is possible. I recognised how a HCSW with a passion for dementia care, often based on some personal experience and core values, demonstrated a commitment to caring, involving the family carer and keeping the patient as the priority. This was demonstrated through examples such as raising concerns of family to medical teams, particularly for those patients with DSD approaching end of life and wanting to avoid invasive investigations; working with family to provide a good end of life experience; honouring families' wishes for their loved one's body when going to the mortuary. There were also ward clerks who provided care for patients with DSD, even though this may not be directly within their role and collaborative relationships with specialist nurses and role modelling good practice. These findings suggest a need for a more collective, and collaborative approach to the delivery of care for people with DSD and their family carers.

The importance of the patient-carer dyad has been discussed in several studies (Braun et al., 2009; Boltz et al., 2023; Kelley, 2019). This study explored how the care of someone with DSD could be based upon the extended dementia care dyad and the Triangle of Care model, building upon the continuous interactions between patents with dementia, hospital care workers, family carers and other patients and colleagues, see Figure 9 (Scerri et al., 2019; Adams and Gardiner, 2005). The findings presented here link with the work of Julian (2022) and Lee-Steere (2024) who recommend training in delirium and involving families should be mandated within organisational policies. This research recognises that families can and want to be involved when someone has DSD, but also that there are few opportunities to contribute, and they are often not noticed by staff. The professional role acts as a barrier and possibly is hidden behind, because staff themselves lack confidence and knowledge about delirium. Lee-Steere's' review, while not specific to dementia, provides similar recommendations and insights to the findings of this study. It also provides evidence of how staff can work with family carers to inform person centred care by participating in the detection of delirium and care of loved ones and family carers across most studies (Lee-Steere, 2024).

Figure 11: Extended dementia care dyad



There were few encouragements, incentives and opportunities based upon the non-participant observations for nursing staff to interact in this way. It had to be a conscious choice; it was not normalised into how nursing practice was provided and overseen. Scales et al. (2017) discuss how person-centred approaches place a considerable responsibility on direct care staff to promote the personhood of individual patients, suggesting such an increased responsibility implies an empowered workforce who can act creatively and autonomously. This, however, often took second place to priorities to get key work done, such as medication rounds and ensuring patients were safe. Consequently, good care relied on what unqualified staff had learnt, a more unpredictable situation that did not encourage a shared understanding between staff and family of how to respond to DSD and reduce its impact. All participants, including family carers, noted that the high-pressure environment frequently resulted in priorities being dictated by tasks.

Environments of care that support or hinder the recognition and reduction of DSD

My study found examples of good dementia and delirium care, identified primarily through an appreciative approach stressing what worked well. The interviews, by using emotional touchpoints, enabled participants to be positive about their knowledge often despite the difficulties some staff faced with certain wards and practices. It was evident that HCSW appreciated and observed emotional distress, more so than the qualified staff and responded to supporting patients through providing activity and reassurance. The use of emotional touchpoints supported staff to talk about their experience and knowledge in a way that connected with their emotions, was curious, and helped them to consider other perspectives. They were able to reflect on the things they did well, recognise the influence they had on others and how they had and could go onto influence care and culture. It began the conversation about how to work collaboratively and to consider compromises.

The terms patient-centred and person-centred are used interchangeably. However, the terms have different origins: ‘person-centred’ originates in the work of the psychologist Carl Rogers and describes a particular approach in psychotherapy. Person-centred therapy gets its name from the fact that its focus is on the client's subjective view of the world. But as the sociologist Nikolas Rose (1998) has illustrated so well, vocabularies taken from therapeutic contexts are increasingly used across a much wider range of contexts and practices. The work of Pilnick (2023) suggests that the pervasiveness of Patient Centred Care (PCC) is not grounded in empirical evidence, suggesting instead it is a moral position that makes intuitive sense. The tension arises when person-centred care as a one-to-one encounter is attempted within a system that may not have the same ethos. Cultural change in healthcare depends on explicitly recognising the relationship between caring and culture and enabling frontline staff to engage in a way that promotes empowerment. These relational processes are to a degree somewhat demonstrated in this study. They are crucial to ensure that strategies, structures and processes advocated by more transactional and unidirectional models of cultural change happen in practice (Bate et al., 2008; Patterson et al., 2010).

The whole crusade of person-centred care was, and is, about challenging and unsettling a health and social care system that is not emotionally intelligent (Sheard, 2022). The original Very Important Persons Framework (VIPS) definition (Table 26) (Brooker 2004) was a reaction to policy definitions in the UK, at the time PCC was simply interpreted as individualised care (Hanley et al., 2016). This was a stark contrast to the groundbreaking work of Thomas Kitwood in the 1990’s who first used the term in the context of dementia care. Significant improvements have been made in the last 30 years, however Sheard, 2022 discusses how the movement has failed to implement a shared view of a person-centred philosophy to its workforce

The findings of this study resonate with the work of Casarez and Smith (2023), who explored associations between hospital organisational features, PCC and nurse sensitive outcomes for persons with dementia in hospital. While not specific to DSD, findings described a lack of standards guiding the creation of PCC outcomes for persons with dementia in the acute care setting. They also identified that no matter the effectiveness of the dementia training, organisational changes and culture shifts are necessary for sustainability over time. Finally, the review highlighted the importance of implementing and studying face-to-face dementia competency training as a standard practice among acute care facilities and the importance of leadership engagement, support and involvement is needed to improve nurse confidence.

Table 33: VIPS Framework, taken from Brooker and Lathan 2016

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

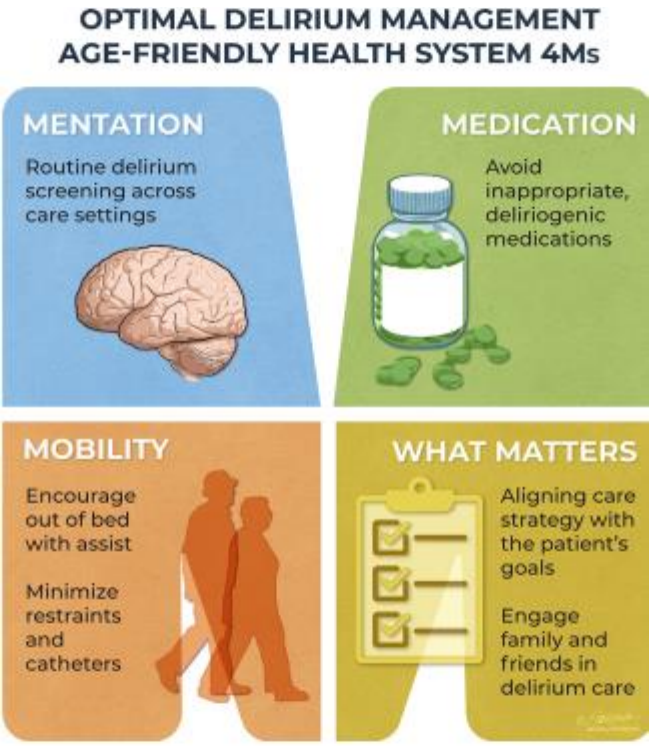
I: An individual approach, recognising uniqueness

P: Understanding the word from the perspective of the person identified as needing support

S: Providing a social environment that supports psychological needs

The Age friendly hospital system (AFHS) environment model, using the framework of ‘4Ms’: what matters, mobility, medication and mentation (Kwak et al., 2023) (Figure 12) is designed to support practical person-centred care for older adults. This framework has the potential to bring PCC to the forefront of dementia and delirium care within environments such as the NHS. The challenge arises when this way of working is not normalised within the culture of the organisation, made mandatory within education programmes and requires senior leadership to ensure implementation and sustainability.

Figure 12: 4 Ms Framework – Kwak et al., 2023



Reframing PCC versus Risk

Findings demonstrated that the challenges for some staff, their perception of their role and the barriers to providing care that was person centred was impacted heavily by the level of patient risk management attached to their roles. Examples of agency staff driven by the need to maintain safety, for example preventing falls, often led them to focus on risk of harm over any intervention to uphold PCC. The work of Pilnick (2023) describes evidence for PCC in NHS service delivery might suggest there is a strong evidence base however, examining the evidence for PCC including Cochrane Systematic reviews (Dwamena et al., 2012), does not show a clear link between the integration of PCC in a setting and a parallel improvement in health outcomes. Pilnick offers an alternative solution, to begin by recognising medical expertise/medical authority as driving how care is organised. She campaigns for a better understanding of PCC as an interaction between healthcare professionals and patients, to inform policy not simply using PCC to judge the success or failure of the policy itself.

What was observed in this study was the embodiment of risk rather than the integration of risk into PCC. PCC and relational care are integral to compassionate care for patients with DSD. Based upon my professional experience and practice and the research findings, the search for more training, better training to fix gaps in practice, staff performance and addressing poor ward culture is often seen as a solution. Handover is one area of nursing care that has come under scrutiny over many years, a practice that is a critical component of effective teamwork (Gaing et al., 2024). Lee-Steere et al., 2020, identified that the practice of handover was variable, with information sometimes misinterpreted. Some participants suggested information was contradictory between staff, making them uncertain and less likely to engage. It was identified during this study that written information was received warmly by participants, this included bedside patient information boards, individualised exercise programmes and brochures. The importance of recognising who they were and embedding this into their care was emphasised. A risk averse staff culture and lack of permission giving was also indicated as a barrier to participation for patients describing not be able to mobilise independently. Abbott et al., 2022, in describing a service change for patients with Dementia in Hospital, identified the need for including person centred information in a shared place on the ward, not just information about clinical care and risk.

While the Dream phase of this study was often a time for self-reflection for some participants, and enabled them to consider what they did well, it was also a time for understanding what PCC and relational working meant to them. Examples were shared through interview and witnessed during observation of the need of unqualified staff to feel involved in-patient care. For example, this included handover practice which some participants described as very limited and did not involve the more person-centred aspects of care. This area of care in DSD is one that requires future work as the study clearly demonstrated the benefits to the staff involved of having opportunities to discuss what could be improved.

Post pandemic ward environments

During non-participant observations, I witnessed vivid examples of how patients with DSD interpreted the environments they were within. Despite some dementia friendly wayfinding and specialist units to support the older person considerations of what constitutes a dementia friendly environment may not cover delirium friendly. How some patients may perceive a sign, a door and how they orientate themselves is very different and requires the need for staff to take a step back and look at the whole person, with families' involvement. There were unintended consequences from post pandemic changes to the environment. Dividing plastic doors had been introduced between bed spaces for infection control purposes. The ongoing COVID-19 outbreaks on wards which then puts patients without COVID-19 into contact-isolation, therefore lead to reduction in visits/visiting hours and longer length of stay. This as a result adds to the risk of developing delirium or in fact worsening DSD that may already be there. Staff in this study did not appear to recognise this risk or feel they had the power to do anything about it. Family carers raised concerns around the isolation of the person living with dementia also experiencing delirium. For some patients, who may not have the ability to use the nurse call bell, they may shout out for help and risk not being heard. Family carers felt space was too small and there was less interaction generally.

The study brought to the surface how valid concerns about infection management had overruled attempts to reduce anxiety and encourage staff engagement. To mitigate this required a senior practitioner to reset what mattered and ensure that there was a shared conversation. Other studies have found the role of a clinical champion for dementia and delirium care. In one study, a person-centred care trained nurse champion, when compared to usual hospital care, identified a significant reduction in behavioural and neuropsychiatric symptoms. There was also a significant reduction in delirium at time point 2, but this was not sustained over a longer period of time (Chenoweth et al., 2024), Delirium prevention champions (Radhakrishnan et al., 2021), and Dementia Care Pointers for service change and dementia champions (Abbott et al., 2022) have been used in other studies. However, in this study, due to the nature of the pandemic, champions often didn't feel heard or could change practice because pandemic regulations trumped other considerations.

The study identified pockets of good practice, which appeared to come from the ward leader down and the passion of individuals working there. Demonstrating that good practice was achievable even in situations of pressure and competing priorities. One ward had prioritised the use of a room space, a sensory activity room where patients could sit with staff or their family members. There was additional equipment such as a sensory trolley, a Reminiscence Interactive Therapy Activity (RITA) system and other equipment used for Namaste. Dementia champions on those wards explained that, since the pandemic, they felt restrictions put in place limited what they could do but they tried to role model best practice, ensuring patients with dementia had some meaningful activity and this shaped the general culture of the environment.

How insight from multiple sources can inform handover and continuity of care

Ward organisational context

Person centred handover practices can lead to person centred care because it provides a shared definition and clearly defined attributes and a framework for a transfer of responsibility and accountability of care (De-Lange et al., 2024).

Extensive research has been carried out on improving handover practices, but little attention has been paid to the involvement of patients and their family/significant others in the practice (Tortosa-Alted et al., 2021). It is argued however, that person-centred handover practices that include patients and significant others improve person-centred care delivery (White-Trevino & Dearmon, 2018). Future studies can consider whether there could be a more structured framework to incorporate the needs of patients with dementia and DSD drawing on family knowledge and insights. The study also highlighted the overlooked role of the unqualified paid carer and how their knowledge informs the handover and related decision making about care.

This current study highlighted handover took place in different formats for different members of the MDT with competing demands. During the non-participant observation phase, when feeding back on my visit to the nurse in charge, they felt that as nursing staff they were repeating the same information at different points in the day and due to time pressures HCSW were most often not involved. Nursing handovers were dominated by narratives of risk, for example of number of patients on a Deprivation of Liberty (DOLs), number with pressure injury, number with Learning Disability or Dementia, mental health concerns and high risk of falls. What appeared to have been lost was knowing the person behind the medical condition. Safety huddles throughout the day assisted senior staff to recognise when additional staff may need to be deployed, staff movement, sickness, additional resources to provide enhanced care and request for shifts to go to agency. These huddles were not observed to contain any person- centred elements to care. The study has added to our understanding of the experience of supporting people with DSD and how the current organisation within most of the study wards did not appear to incentivise attention being paid to the spiritual, psychological, social and emotional dimension of the person alongside their medical condition. The process of daily whiteboard rounds focusing on discharges, length of stay and risk currently only focuses on the medical condition and the risks associated with hospital stay and discharge concerns. What countered this were when staff had opportunities to share learning about the patient and these were informal and reliant on individual's confidence and recognition of the significance of their knowledge.

Much research has focused on improving handover practices, but little attention has been given to involving the patient views or those of significant others (Tortosa-Alted et al., 2021). A recent study exploring the definition of person-centred handover practices, (De-Lange et al, 2024) identified how person-centred handover practices may enhance the delivery of person-centred care. For example, to create a shared understanding of person-centred handover practices incorporating PCC, they identified five key elements: 1. A structured, content specific approach, 2. Sharing verbal/non-verbal and written information, 3. Person-centred inter professional activities, 4. Active involvement of patients and their significant others, 5. Dedicated space. These practices have shown to increase patient and staff satisfaction and enhance quality care and patient safety (Chien et al., 2022).

The AI process could be replicated in staff-to-staff conversations, establishing that curiosity is positive, and it is worth giving time to, building relationships between staff and family carers working in partnership to provide support to prevent DSD. The study appreciated the key contribution of (some) of the HCSWs as the member of staff most likely to have that connection and communication with family carers. When HCSW were interviewed, they sometimes felt anxious that this may not be in their role or would be viewed as going a step too far, meaning crucial information about the patient and supporting the family may be lost. For the patients with DSD, the distinction between qualified and unqualified knowledge and skills was blurred. Nursing staff did not always recognise how much of their work could be enhanced by creating opportunities to discuss the details of care with HCSW.

The competing demands to ensure accurate documentation, often meaning staff, particularly those in specialist roles were the people documenting on paper notes and on the electronic system. HCSW did not usually make entries in patient notes. As the health service moves to digitalisation of all records (National Health Service England, 2022; Sheikh et al., 2021), some staff in this study are hesitant about how the details of care will be recorded. The person-centred care plan ‘This is Me’ for patients with dementia for some trusts has been and allows family carer/patient to contribute to its completion. It is unknown how this is being incorporated into patient records and care plans. Since carrying out this research, compliance with the recording of ‘This is Me’ has dramatically reduced, special interventions are being developed to address this, one of which includes a digital copy uploaded to the trust website to enable families to complete ‘This is Me’ and email it to the relevant departmental manager or specialist team. Nationally, a heightened awareness of the importance of this document could enable staff providing care to have an insight into the world of the person with dementia and have improved relationships with families promoting confidence in care. Encouraging the completion of this tool prior to admission is one way of considering this. An approach that has been used successfully for people with Learning Disability and is encouraged in this study site is the use of the Purple Folder, while this is not a national initiative, for example in Hertfordshire, it is used as a health passport for adults with learning disabilities. This folder helps healthcare professional quickly access health information, ensuring better care and communication; this may vary across regions. A folder/health passport for people living with dementia, I believe, would be a positive way forward.

Dream Phase - Relational Constructionism/Communication

Relational communication that recognises the relationships surrounding the patient as well as their individual needs and priorities is a key theme running throughout the study findings.

Effective communication with people living with dementia is believed to rely on staff, not only knowing the person well, but also having positive relationships with them (Clissett, 2013; Feast et al.,2020 and Stanyon et al., 2016). Reflecting on the work of Dewar, (2011) and the Caring Conversations Framework, Dewar extends the ideas of person-centred care to address how staff respond to the patient and each other. She emphasises the importance of emotional connection, courage and collaboration, all of which were apparent in many of the relationships and interactions described and observed during this study. However, the other elements, curiosity, celebration, compromise and consideration of others' perspectives were not always present in what was understood to be a positive interaction. A ward culture that encourages curiosity, i.e. questioning the norm and celebration of good practice is hard to introduce and sustain. The starting point is a shared understanding of the goals of care that involves all ward staff.

The Francis report, 2013, described the need for an increased focus on a culture of compassion and care in nurse recruitment, training and education. An approach that fosters compassionate holistic care is not contentious and important in hospital in dementia and delirium care and delivers high quality outcomes (Krishnan et al., 2024). Von Dietze and Orb (2000) argue that compassion is not just an emotional connection between nurse and patient but requires a moral dimension that directs nurses' decisions and practice. Understanding, identifying and measuring compassionate care outcomes is a complex area. Humanitude, a methodology of care developed by Gineste and Marescotti in 1979, (Henriques et al., 2019), is a relationship-centred and compassionate care approach that aims to support patients, used in countries such as France, Japan and Singapore. It is a care methodology designed to enhance the quality of life for vulnerable individuals such as those with dementia or cognitive impairments. Based on the four pillars of gaze, speech, touch and verticality (maintaining an upright position), which focus on fostering dignity, empathy and connection. This approach has been shown to improve patient well-being, reduce behavioural challenges leading to distress, and even decrease caregiver burnout. Some hospitals and care facilities have adopted Humanitude as part of their training and care practices to create more compassionate and person-centred environments. Research, when comparing Humanitude to normal care, identified significant improvement in mobility, ADL function and well-being for patients with dementia and/or delirium in the acute hospital (Giang et al., 2023). The study site has implemented the care methodology of Namaste, similarly, fostering dignity, empathy and connection. Both approaches share a commitment to person-centred care; although they differ in their specific approaches and applications, they however both complement each other in delivering compassionate care.

Smith et al. (2010), in their research on relationship centred outcomes in compassionate care for older people, concluded that skilled facilitation and leadership were central to the processes used to understand experience and then develop compassionate practices. This raises the question about the capacity and focus of organisations to practically enable such leadership and facilitation.

The review identified that a compassionate approach to care for patients with DSD seemed to be more easily prioritised by volunteers, with registered nurses voicing this then allowed them to get in with nursing tasks. Demonstrating compassion, the review suggested could be separated from nursing work, but the observation and interviews demonstrated the unintended and negative consequences for the patient when the connection with nursing work was lost. A solution that does not address the gap between what ought to happen and what was observed to be the priorities and practices of qualified staff.

Humanising Delirium Care

A blog by Michael Rosen, poet, performer, broadcaster and scriptwriter on his experiences of delirium during an admission to ITU, said he had only just realised that what he heard going on around him was real, it wasn't in his head. Michael spent several weeks in an induced coma and later described visual hallucinations and confusion. His reflections highlight the emotional and psychological challenges faced by critically ill patients and the importance of compassionate care alongside the technical care, a key attribute of excellent dementia and delirium care. Delirium can be a terrifying experience for both patients, family carers and staff. While the study findings identified staff often did not recognise delirium and conflated it with dementia, practical learning from this ICU account from Michael informs the needs for good, kind and compassionate nursing practice.

The fourth conference about post intensive care syndrome (PICS) in Madrid, sets out ten principles for humanising delirium care (Nydahl et al., 2024). This advocates a symptom-orientated patient centred interventions according to FRAMES (i.e. Feedback, Responsibilities, Advice, Menu, or behavioural change, Empathy and Self-Efficacy).

The FRAMES model could be adapted to dementia care to provide patient centred care that could be adapted for people with dementia and linked with family involvement.

Table 34: Ten Principles for humanising delirium care

1. Respect and trust: use patient's name and titles, ensure safety
2. Communication skills: personalised (non-verbal communication techniques with (non-) speaking patients, mirroring, reassuring
3. Empathy, consider patient's view, experiences
4. Personality: ask and listen for experiences and patient's story
5. Acceptance: re-orientate and reframe
6. Accompaniment: Hold hand if appropriate, assess symptoms and tolerance
7. Autonomy: Offer feasible choices, e.g. sitting in a chair, or being in bed
8. Resilience: Ask for personal coping strategies, e.g. information, family prayers and music
9. Safety: Continuous clinicians, explain environment, ensure vision/hearing aids
10. Hope: Integrate family, support personal coping

Taken from Nydahl et al., 2024

Nydahl's framework for humanising delirium care emphasizes person-centred approaches, dignity and holistic care, which can be highly relevant when applied to dementia care with added delirium. The following considers how this could be used in dementia care and the challenges involved:

5. Person-Centred Approach - Tailoring care to meet the PCC of the person with dementia, focusing on the individuals' needs and preference to maintain their sense of identity despite the cognitive challenges.
6. Communication - Simplified communication using an empathic approach.
7. Environment - Creating a safe and calm environment, can help to reduce triggers and prevent over stimulation.
8. Family involvement - ensure they are fully supported to be involved in care and decision making, helping to provide that emotional support.

The challenges around this complicated by delirium on a background of dementia may be:

9. Complexity of Symptoms - Identifying the difference between dementia and delirium symptoms can be complex, leading to delayed or inappropriate interventions.
10. Staff Training - Ensuring all caregivers are trained in both dementia and delirium care requires substantial resources and time, may not be mandatory and delirium training may not be embedded and given the credibility and resources it requires.
11. Emotional Toll - Caring for individuals with both conditions can be emotionally overwhelming for caregivers, leading to burnout.

Considering Nydahl's framework and incorporating elements of Namaste Care, approaches to therapeutic intervention, compassionate care, addressing fundamental human needs and relational working, drawing on the work of others, a suggested framework of support which can inform care planning as a suggested use to support patients with DSD in acute care is presented in Text Box 5. This could also be transferable to other settings and elements of this are currently being developed and supported across other hospital sites.

Table 35: Humanising care for patients with dementia and delirium (Ashton-Gough 2024)

Intervention	Source
1. Respect, understanding and trust: Use patient's name, find out the name they like to be called, use titles if relevant such as Dr, Professor	
2. Communication: Complete a Life story document such as 'This is Me'	Alzheimer's Society, 1553 This is me
3. Communication: Ensure patient has access to hearing aids/glasses, ensure access to non-verbal communication aids if patient non-verbal	Morandi et al., 2021; McCusker et al., 2001
4. Communication, consider loving touch, holding hands	Namaste Care, Joyce Simard
5. Relational Care: Involve family, ask "Is this usual for your relative?"	Adams and Gardiner, 2005; Nolan and Keady, 2001
6. Empathy: Being in their shoes, imagine how they might feel	
7. Fundamental human needs - Prioritise/identify at every intervention, when needs not met can cause distress leading to behaviours that challenge, this includes: a) Physical comfort and freedom from pain, b) Perception of Safety (can lead to feeling unsure unsafe), c) Positive touch, d) Love and belonging , e) Esteem needs, f) Control over environment and possessions, g) Fun (we all share the need for fun) and h) Occupation/Exploration (may include excessive walking)	The Cait (Communication and Interaction Training) Model of Dementia Care, James and Gibbons 2019.

8. Safety: Identifying the risks, speaking to family, support PCC and aim to integrate management of risk	
9. Well-being: music therapy, pet therapy, dementia volunteers, Namaste	Cheong et al., 2016; Walsh et al., 1995 Simard and Volicer, 2010
10. Validation	Feil, 1991
11. Autonomy: Include patient in decision making, e.g. food choices, getting out of bed, walking to toilet	
12. Communication: Professionals' careful use of language, e.g. use walking with purpose, not "wandering", use distressed behaviours instead of "aggression"	James and Jackman, 2017
13. Symptom management: Use Abbey Pain Scale to accurately identifying pain, rationalise use of pharmacological interventions, opting for non-pharmacological if able	Abbey et al., 2004 APS_Pain-in-RACF-2_176pp_Full-Proof_21AUG18
14. Addressing the impact of the cycle of night and day, i.e. sundowning may increase confusion, agitation and restlessness	Sundowning and dementia | Alzheimer's Society

Reflections on theoretical approach

Relational constructionism stimulates the creation of collaborative relationships between members of organisations opening and discovering new perspectives to act and create changes. Using a relational constructionist stance to enhance the Appreciative inquiry framework to this study illuminated my findings, not just in terms of what was discovered, but how to understand and engage with those discoveries. It shifted the research paradigm from extracting the objective truth by exploring and enhancing the culture of care for patients with dementia and delirium to co- creating meaning through relationships, dialogue, and context appreciating things that worked well.

Using RC encouraged inquiry that opened up possibilities, findings became more dynamic, evolving insights shaped by the relational context in which they were produced. This allowed more humanised interpretations, richer, layered understandings and the space for multiple truths and perspectives. There was greater space for turning the research into a conversation, not a process or a monologue. Participants became co-inquirers, not just subjects. This then led to a greater authenticity in the data and empowered voices, especially from marginalised groups such as those of the Health Care support workers.

Contextual sensitivity enhanced through relational constructionism emphasises that meaning is not fixed or "always situated", in a singular, pre-existing context. This led to the findings being more relevant and applicable to real world settings, attuned to cultural, social and material conditions and less prone to over generalisation. Most importantly for this study this approach in the role of researcher allowed me to reflect upon my own assumptions and how this shaped the inquiry, the ethical implications of my methods and interruptions and the impact the research had on the participants, the setting and the community. The transformative potential it has led to and will continue to lead to practical change.

In the NHS, looking at what's working well and really trying to understand what it was that was working well is not the norm, for the 97% of things that do go well we don't have the same gaze. For some, recognising what's working well sometimes the participants found it hard to articulate, its counter cultural, but it's what really being curious about what we value and what really matters to us. Some may think positivity can be a bit false considering the pressures we face, and for some staff hard to see the positive through the challenges faced every day. But if we also add in there what we care about, what we value, what matters, it makes us feel we can achieve at least the little things (those person-centred moments of good practice). What do we really value, saying it in a different way, reframing, not having that defensive attitude.

Reflections on Methodology

Strengths and limitations of the study design were articulated in Chapter 3. This section reviews methodology considering the findings that have emerged. Several strengths in the design give weight to the findings and the conclusions drawn. In addition, new insights about the approach of AI are highlighted.

The AI Process

AI is a relatively new research approach for exploring and developing nursing practice. Few studies have adopted this approach in the context of care for older people (Watkins et al., 2020) or exploring experiences of patients with dementia, not specific to delirium. For studies that looked at delirium superimposed on dementia but have not adopted the AI approach (Julian, 2020), provided an in-depth qualitative description of the experience of family carers supporting family members with DSD.

Those that have used it (see Reed, 2010) have focused on its implementation for service development with larger multidisciplinary groups.

Starting out in this study process and exploring the right methodology to fit with both myself as a nurse/researcher and the study group, led me to the work of Belinda Dewar and her thesis on Compassionate Conversations; this resonated with the approach I have chosen.

Appreciative inquiry facilitates a positive approach to leadership development and organisational change. Its focus is on identifying what is already working well, rather than looking for problems and trying to fix them. What is important in my professional role is to recognise the positive core strengths of people, such as core values, best practices and aspirations. Dementia care in hospital is often poor, and not recognised as skilled work (Handley et al., 2019); staff have little understanding of person-centred dementia care, and organisational and environmental constraints prevent staff delivering good care. Using AI allowed me as a researcher to explore those core values and strengths, recognising this is how others learn. Using the approach of AI supported this method.

AI follows a four-phase cycle, known as the 4-D model: Discovery, Dream, Design and Destiny. This study focused on the first 2 phases.

One strength of my study is that combining non-participants' observations and interviews enabled me to develop a detailed understanding of current practice and highlight the positive things, those compassionate, person-centred interventions that worked well. Van Graas and Gobbens, (2023) explore all 4 phases in a study in care home setting with one team. However, there are still few examples within single studies of how AI leads to practice changes. Further exploration of this methodology, as it relates to practice change and improving sustainable outcomes in the healthcare context, is needed.

AI literature reports very little about approaches to data analysis and important issues that emerged from using the analysis framework of immersion/crystallization. The immersion/crystallization framework, (Borkan, 1999) fosters deep engagement with qualitative data. In this study, by grounding the analysis in key reflective questions participants became empowered in reflecting on and analysing their own data. This approach cultivates a sense of curiosity and provides a supportive framework for data analysis. Most significantly, this approach boosted participants' confidence and has encouraged them to advocate for their patients or relatives and implement improvements based on their insights.

The Appreciative Inquiry framework encourages a culture that builds relationships, inclusion and a shared belief in the value of learning from best practice to improve practice. Using the tools of AI, I have learned to focus more on doing with rather than doing to, i.e. teaching, it's important to hear from staff and family carers and listen to what they need without making assumptions and the ongoing importance of role modelling best practice. The stories and additional insights that have come from this approach have helped to transform lives, experience and can have a major impact on our culture, our services, and our everyday practice.

Emotional Touchpoints

The method of using emotional touchpoints to support data collection played an important role to build understanding of what people with dementia experience and can be part of a broader approach to measuring the wellbeing of people with dementia (Dewar et al., 2010; Alzheimer's Society, 2019).

Using emotional touchpoints with staff allowed me to understand how staff feel about their work, what motivates them, what challenges they face and how they cope. Emotional touchpoints as a framework facilitated a way of engaging, for both me and the participants, to feel safer emotionally, and helped people to be confident using a language that asks us to share explicitly how we feel about an experience and why.

Transferability of findings

The study site was already selected prior to its commencement. The wards identified for the non-participant phase of the data collection were selected due to the number of patients identified with dementia and delirium; no ward was excluded, unless they did not have the cohort of patients required. The findings are relevant to other hospital sites.

The rich descriptions of the cultural context and research methods means that readers can assess the relevance of the findings to their care settings (Sharp 1998). This study is thus orientated to analytical generalisability rather than statistical generalisability, appropriate given the theory-generating nature of the research.

Different levels of engaging with participants

As the study progressed, the views primarily of staff, both registered staff and healthcare support workers and non-clinical staff, focused on their experiences working on the wards. What had not been fully anticipated was the number of staff who were also family carers supporting a person with dementia who had experienced delirium. Understanding how this affected their workplace decisions as part of the data collection validated an approach that encouraged reflection and was sensitive to participants' wider life experience. They were asked during interviews what would make dementia/delirium care better, or to describe a time when their experience had been different. It was therefore possible through the approach to involve family members, who were also professionals enabling them to be supported, to share their feelings.

Doing research in relation to caring relationships

Emphasis on interdependent relationships served as a useful theoretical foundation for this study. It encouraged me to explore, not only perspectives from all social factors involved in providing care for patients with DSD, but also to look at common elements that helped people give and receive care and consider interventions that have potential application across all three groups. This dimension resonated with the paradigm of relational constructivism, discussed in Chapter 3.

A strength has been that data generation, analysis and considerations for implementation have focused on all three groups in relation to one another. Therefore, these findings present evidence of the relevance of the model for all three stakeholder groups.

Developing the role of the appreciative Inquirer

Collaboratively exploring what matters to people, their understanding of concepts and their ideas for innovation was key to my role as an appreciative inquirer. One of the key skills I used was constant reflection and looking from the outside in to separate my role from that of clinical nurse to that of researcher and appreciative inquirer. As an appreciative inquirer the intensity of being appreciative all the time was challenging, when trying to think of and how to respond to negative situations, especially during the non-participant observation phase (Merriel et al., 2022). Suspending professional judgement and asking curious questions required self-discipline. On-going reflection, considering the choice of language when asking questions during the interview phase, was instrumental in managing the tension of being a researcher and a clinician. This experience has had limited attention in the literature. One review of AI as a research approach has challenged how much it leads to positive patient outcomes, even when data suggests it improves how staff and patients involved feel about the care provided and received. The authors conclude it is possibly better suited to quality improvement initiatives.

Hornstrup and Johansen (2009), articulate the suggestion of foregrounding inquiry as a relational and linguistic process. They advocate moving the idea of AI as a noun, to the verb of inquiring appreciatively, where it is recognised as a relational process that occurs with day-to-day interactions with conversational moments. I consider this more accurately describes what the staff in my study did while reflecting on practice.

The next section summarises the implications of the findings for policy, research, education and practice. Issues raised are of relevance to practitioners, practice developers, managers, educationalists, researchers and policy makers in the field of care for people with dementia who experience delirium and, more generally, for those concerned with enhancing quality if the healthcare experience for patients with DSD in hospital through specific change or quality improvement methodologies.

How the theoretical approach has illuminated the findings

Using relational constructionism as a theoretical lens in this thesis profoundly illuminated the findings by shifting from the individual pathology of dementia seen in many dementia and delirium studies to the social and relational dynamics that shape experiences of care. Relational constructionism views reality which includes identity, meaning and experience as co-constructed through relationships and interactions. In the context of dementia care this gets us to objectively see the individual with dementia viewed as a person with a strong sense of self and a sense of well -being shaped by ongoing relational processes and not individual in isolation with cognitive decline.
It reframed identity and personhood as the core of understanding relational interactions, instead of seeing dementia as a loss of self, relational constructionism allowed a richer exploration of how personhood is maintained or reshaped through interactions. The reframing of these moments gave me a deeper insight when undertaking non-participant observations, exploring those emotional connections between patients and their family carers which over wise may have been overlooked.

It highlighted for me the role of language and interaction, particularly when observing and listening to nurses delivering fundamentals of care at the bedside. Those moments of emotional connection, trying to delve deeper in understanding how care tasks were not always just physical tasks but linguistic and relational performances. Analysing how care practices were enacted though touch, talk and shared routines, shaped for me a deeper insight and understanding and sometimes helped reframe those biased interpretations of care, identifying those precious moments of a sense of maintaining personhood and dignified care.

Lastly, it helped to expose those power dynamics, there were examples of how institutional discourses, i.e. the medical model of care versus risk management etc shaped the way care was delivered and experiences, these critical insights illuminated a deeper understanding in how staff navigated the constraints of the organisation while trying to delivering a standard of care they aspired to and build meaningful connections with their patients, often voiced as not being seen as an important part of care.

Implications for Policy

In May 2022, Sajid Javid, the then Health Secretary pledged to deliver a National Plan for dementia. Despite this announcement, later in January 2023, the then Health Minister Steve Barclay announced a major conditions strategy instead. While there may be the opportunity to influence this strategy to reflect the needs of those with dementia, without fixing social care alongside this, it will fail. Current Government initiatives for the NHS, such as reverse boarding, a process used to manage overcrowding in emergency departments (EDs) and assessment units. It involves identifying patients on hospital wards who are either ready for discharge or well enough to temporarily move to another area, such as a day room or corridor. This frees up bed spaces for patients waiting in the ED or assessment areas, ensuring that critically ill patients can be accommodated more quickly. A Royal College of Nursing Report, Wise (2025) highlighted the alarming normalisation of this practice in the NHS; the report surveyed 5,400 nursing staff and revealed more than two thirds of staff who responded experienced this practice daily. The report highlighted issues with patients not receiving dignified care, receiving confidential information in public spaces and not having access to basic needs such as going to the toilet. Williams, (2023) highlighted corridor care negatively impacts on patient safety, staff well-being and overall outcomes. They suggest systemic interventions are needed to prevent overcrowding, while offering practical strategies for nurses, such as safety huddles and observable rooms, as an attempt to enhance patient safety, thus enhancing family care experience. At the study site, staff within the department have made real attempts to consider these challenges, recently redesigning their observable bays and considering what more can be done.

While the impact on patients with dementia and delirium has yet to be examined, what we already know about dementia care in hospital, the impact of a changing environment and the breakdown in care, when we don’t know the patient and their family well, suggests this is harmful, for the patient from a safety perspective, for the family carer from a familiar concern about lack of compassionate care, and for staff who are already under mounting pressure.

Internationally, the case is being made for more single room accommodation in new hospital designs. Much evidence originates from the USA and Scandinavia (Ulrich et al., 2008, West et al., 2010), with some researchers arguing for the abolition of all shared accommodation (Maben et al., 2015, Pennington and Isles, 2013). New hospital designs are increasingly incorporating single rooms to enhance privacy, dignity, and infection control. However, this approach has mixed implications for people with dementia:

- **Isolation**: Single rooms may trigger feelings of loneliness and enforce reduced social interaction, which can negatively impact emotional well-being.
- **Monitoring Difficulties**: Staff may find it harder to observe and respond quickly to patients in single rooms, increasing the risk of falls or delayed in receiving care.
- **Wayfinding Issues**: Patients with dementia may struggle to find the way to communal areas or bathrooms, leading to disorientation and frustration, leading to feelings of distress and resulting in unmet needs.

To address these issues, there has been discussion with services, experts by experience and other professional groups such as the Alzheimer’s Society and Dementia UK. However, how much this can influence change is not clear. To mitigate the risk, hospital designers have suggested that there will need to be:

- **Dementia-Friendly Design**: Incorporating clear signage, familiar decor, and accessible layouts can help patients feel more oriented.

- **Staff Training**: Equipping staff with skills to engage and monitor patients effectively in single-room settings.
- **Assistive Technology**: Using monitoring systems to ensure patient safety without compromising privacy.

While single rooms offer many advantages, careful planning and design are essential to address the unique needs of people with dementia. New hospital design as explored by Park, (2024), hospital space interpreted to Heidegger's concepts of care and dwelling shines a spotlight on the loss of caring spirit in the design of new hospital builds affecting how new hospitals are conceived, built and managed as well as the human experiences within them (Park, 2024). Hospitals are a place where life can fall apart as well as the joy of being cured of a disease. Despite being deeply associated with human survival, the need to treat diseases proficiently has led the modern hospital to become a technical treatment orientated space that focuses on the disease rather than the patient with the disease. Care goes beyond the act of treatment.

Implications for Research

Areas for future research identified by the study include:

- Building on the understanding of how the physical environment in hospital requires additional consideration for patients with delirium or DSD, more than just dementia friendly
- New Hospital design, what is the evidence that single rooms will provide care that is holistic and will improve outcomes for patients with DSD
- Exploring the role and integration of the HCSW in formal methods of ward communication and staff to staff working
- How family carers and their relationships working with healthcare professionals and unqualified staff can be developed to improve outcomes for patient with DSD
- To explore how culture of the organisation, its compassionate approach to care can influence staffs' approach to dementia and delirium care
- How a framework to support relationship centred care for people with DSD may help staff, family carers and the patient receiving care

- How Nursing education programmes need to reflect the diversity and culture of the workforce
- The impact of reverse boarding on dementia and delirium care
- Family carers interpretation and crossover of symptoms relating to DSD/BPSD

Implications for Education

Findings suggest that while education and training was available, uptake was variable dependant on individual interest or in response to a learning need, staffs' personal interest, as a part of the Dementia Champion programme and the facilitation of time of the ward. Staff conflated dementia and delirium and were largely unaware of how little they knew. There was some evidence to suggest that there was a difference in practices and responses between nurses from different cultures. It was a perception and part of a much bigger finding that staff who provide the best person-centred responsive care were those who spent most time with patients, i.e. the unqualified and /or had personal experience of a family member with DSD. Findings highlight little evidence that staff are not always equipped to learn how to work with and support family members of patients with DSD or focus on how education about reducing the risk of delirium could be better supported.
There needs to be an importance placed on the need for delirium education for all staff that combines experiential learning with formal teaching and review.

Implications for Practice

There is real value to support and build on aspects of practice that were shown to work well. It is argued that this helped create cultures of hopefulness rather than helplessness that can be felt when the focus is on what is not right with practice. Specific strategies should be put in place that encourage positive discourse.

Both implementing person centred dementia care through relational working and culture change require that relational practices are acknowledged as a key skill that needs to be valued, promoted and supported in the workplace. Some of the practise that emerged from the study that promoted person-centred/relationship centred care would be easy to replicate in other wards and other hospitals; for example, having access to sensory equipment, developing the roles of compassionate care/Namaste care volunteers and Namaste approach to care. For this to be replicated would require a sense of shared values, leadership, culture and a philosophy of compassionate relationship centred care.

This study has shown that AI facilitated learning and the “knowing how” from practice. Given the increased call in NHS Boards for the sustainability of outcomes from projects initiatives, those involved in quality and Continuing Professional Development Programmes should consider this approach.

The emotional impact of caring, for patients with dementia and delirium inherent in the processes described in this study, needs to be acknowledged and celebrated. In addition, appropriate strategies need to be put in place to encourage expression of this in everyday practice.

Strong, consistent, compassionate, knowledgeable and reflective leadership that models compassionate relationship centred care in dementia and delirium needs to be recognised as one of the key factors enhancing the quality of care. Senior nurses and supervisory positions have the opportunity to enable closer working relationships with their staff and their patients supporting and role modelling direct patient care.

Chapter Summary

This study, unlike many others that have examined delirium incidence and prevalence, screening tools and clinical outcomes has focused on the fundamentals of care. Picking up on the theme from World Delirium awareness day 2024, Humanising Delirium Care, it has been important to explore and include family carers and staff views about what informs compassionate and relationship centred care for patients with DSD.

It has also highlighted the need to value an environment that creates a culture of care and one that staff feel confident and have a sense of pride to work in. Staff need to feel they have a voice, and that patient care should take priority.

Chapter 7 – Researcher’s reflections

Introduction

The final chapter will address:

- What being reflexive in research achieves.
- Dual role as a practitioner researcher.
- How my clinical knowledge informed my observation and particularly noting what did not happen (e.g. a non -clinician would not have considered hypoactive delirium). How the gap was reconciled between what ought to happen and what was observed.
- Emotional Intelligence.
- The emotional cost of observing poor practice.
- Whether AI made the process more difficult or was a support and why.

What being reflexive in research achieves

Many definitions of reflexivity exist, leading researchers to feel confused and as a result affect the knowledge and confidence to apply this. Olmos-Vega et al., (2023) inductively analysed qualitative logical data descriptions of reflexivity, see examples in Table 31 and following this formulated the following definition:

> “Reflexivity is a set of continuous, collaborative, and multifaceted practices through which researchers self-consciously critique, appraise, and evaluate how their subjectivity and context influence the research processes” (Olmos-Vega et al., 2023).

Table 31 - *Commonly cited definitions of reflexivity from the field of qualitative research (taken from Olmos-Vega et al., 2023)*

Reference	Definition
(Walsh 2003)	“That which turns back upon (or takes account of) itself or the person’s self”
(Dowling 2006)	“The analytic attention to the researcher’s role in qualitative research. A continuous self-critique and self-appraisal where the researcher explains how

	his or her own experience has or has not influenced the stages of the research process.”
(Gentles et al., 2014)	“The generalized practice in which researchers strive to make their influence on the research explicit -to themselves and to their audience
(Finefter-Rosenbluh 2017)	A continual internal dialogue and critical self-evaluation of the researcher’s positionality (Pillow 2003), which leaves the researcher changed in its wake (Mauthner and Doucet 2003).”
(Russell and Kelly 2002)	“A process of honouring oneself and others in our work through an awareness of the relational and reflective nature of the task.”
(Finley 2022b)	A thoughtful, conscious self-awareness that encompasses continual evaluation of subjective responses, intersubjective dynamics and the research process itself”
(Kuehner et al. 2016)	“A strategy of using subjectivity to examine social and psychosocial phenomena, assuming that social discourses are inscribed in, and social practices are embodied by the researcher.”
(Malterud 2001)	“Attending systematically to the context of knowledge construction, especially to the effect of the researcher at every step of the research process.”

Reflexivity is the process of reflecting critically on oneself as a researcher (Bradbury-Jones, 2007) and is central to the construction of knowledge in qualitative research (Narayanasamy, 2015). It requires the process of knowledge construction to be the subject of investigation (Flick, 2019). Reflexivity is concerned with acknowledging your role in the research. As a qualitative researcher, you are part of the research process, and your prior experiences, assumptions and beliefs will influence the research process.

Typically, reflexivity involves examining your own judgments, practices, and belief systems during the data collection process. The goal of being reflexive is to identify any personal beliefs that may have incidentally affected the research. During reflexivity, you must be prepared to question your own assumptions.

Dual role as a practitioner researcher

The boundary between my role as an experienced Registered Nurse (RN) and Dementia Clinical Nurse Specialist (CNS), and my role as a novice researcher raised some thought provoking and challenging matters for me. I considered that my experience as a Dementia CNS, experience of working with people with dementia and their family carers, managing teams of staff and previous research experience in the hospital setting, would prepare me to some extent for undertaking this study. On reflection, I had not anticipated all the ethical and clinical scenarios and the emotional impact that I encountered when undertaking non-participant observations during the fieldwork stage. My professional background and belief systems inevitably influenced my interpretation of events in field work and data analysis. This was countered through supervision and reflection on different explanations for what was being observed. It was evident though that my professional status had competing influences.

Firstly, my professional background and employment within the organisation promoted my credibility with the Research Team, Senior Managers and staff working within clinical environments and had an impact on engagement with the research. For example, there was a lot of interest in the research and how this would help make improvements in dementia and delirium care. Additionally connecting a meaning to a participant story or making a clinical judgement was supported by my professional role. However, all social research is inherently biased by the positioning of the researcher (Bushe, 2011, Conneely, 2002, Cooperrider et al., 1995, Reed and Procter, 1995). I remained duty bound by the NMC Code of Conduct (2015) and attended regular academic supervision through the study, to enable me to discuss clinical encounters and the challenges of developing research skills.

To promote transparency in my role as a practitioner researcher:

- I attended relevant nursing forums such as ward manager meetings to discuss my role/research.
- I met with ward staff before undertaking non-participant observations and spent time with the MDT.
- Participants knew that I was not assuming a clinical role, and I was careful to ensure the boundaries of my clinical role/research role did not become blurred.
- I maintained a reflective account of situations within a diary format (see Appendix 15 for an example), an account of how my own values and standards and interpretations influenced the research process throughout my fieldwork to promote ethical transparency (Luff et al., 2015).
- This was a regular topic for discussion in academic supervision.

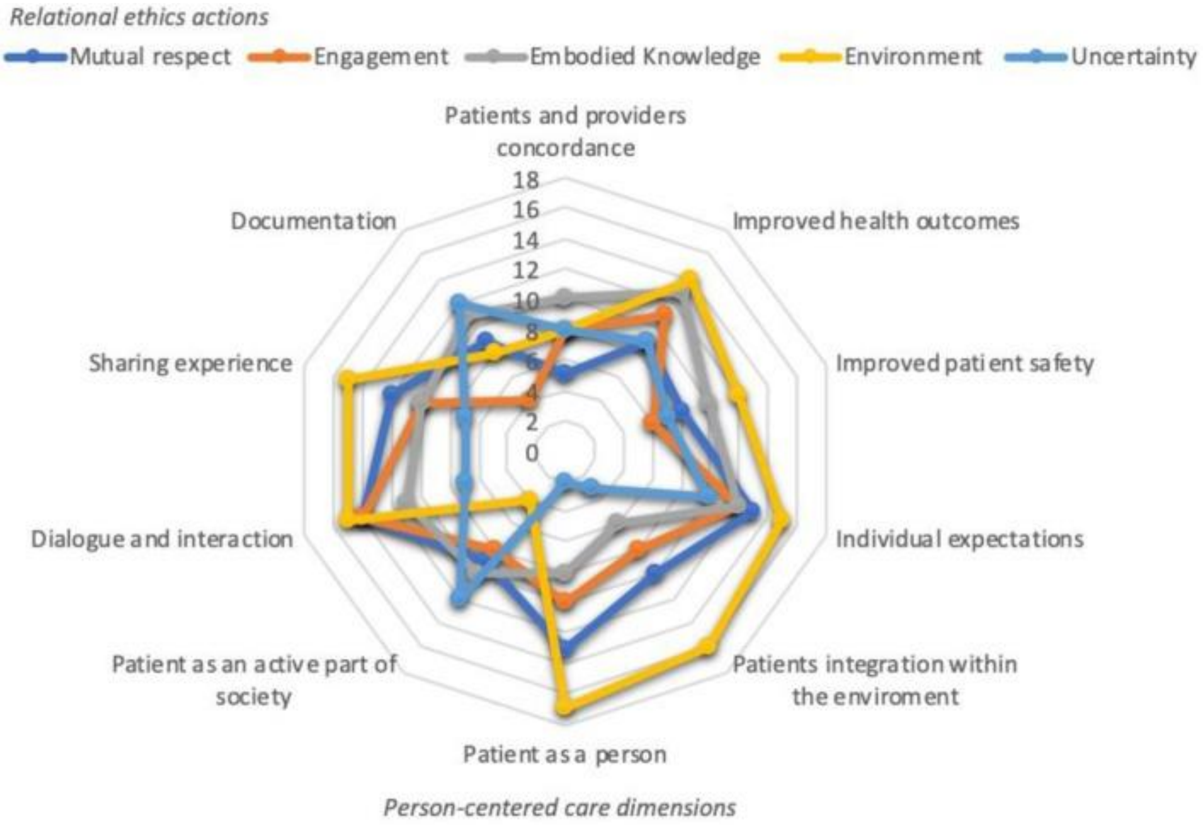
Tension between my own values and beliefs and clinical knowledge and my research findings led me to some anxiety, internal questioning and self-doubt. As a clinician I recognise and I am immersed everyday into the challenges staff face caring for patients with DSD, I witness the rapid turnover, workload and environmental challenges they face. I understand the challenges we are faced with, a nursing workforce of over 76% from overseas, therefore making communication and understanding of dementia difficult. I also did not appreciate how revealing non-participant observations would be in terms of practice that could have been better, lack of recognition of DSD, response to distressed behaviours and attention to unmet needs. However, I have my own standards of care, a moral duty to the patients and families I support, I internally challenged myself often, asking myself, “am I expecting too much?”. Striving to deliver person centred care through relational working remained a priority for me but often appeared to falter with others.

The most important relational ethic action referred to in combination with PCC features is environment (referred to as a person’s integration within a social environment/community). This is followed by mutual respect, engagement and embodied knowledge. These were the salient relational ethics actions both directly and indirectly linked to PCC. Tomaselli et al., (2020) linked the two identifying similarities between PCC and relational ethics, Figure 13.

The research questions and the resulting design and methodology reflect my desire to focus on the extant possibilities that compassionate relational care can improve the lives of people living with dementia who experience delirium, and this in turn support their family carers.

I recognise that I have a strong bias for hearing the voices of people living with dementia and their families and understand how the experience of hospital care for people with DSD is influenced by the culture, the compassion, the relationships we provide and the knowledge and skills of the staff providing care. Within the broad concept of ethics, I recognise how the relational ethics theory assumes a key role in PCC. Building on the work of Bergum and Dossettor (2005) and Pollard (2015), relational ethics refers to those relationships which are considered as better that others and aim at stimulating growth, healing and health. Furthermore, according to Evans (2004), relational ethics is defined as action ethics that is placed within the interpersonal relationship encompassing engagement, mutual respect, embodiment and environment.

Figure 13: Similarities between PCC and relational ethics



Tomaselli et al. 2020

The academic supervision has been supported by supervision in my role as an Admiral Nurse through Dementia UK for this past year. It was evident though that, while my professional status substantiated my credibility with the hospital staff and managers and may have had an impact on the way I encountered clinical practice, nurses conducting research in their own clinical practice face a range of emotional challenges which include anxiety, negative feelings, emotional investment and emotional labour.

The desire but complexity at times, experienced through a passion, drive and determination to improve the lives of people living with dementia, and particularly those experiencing delirium in hospital and supporting their family carers has been integral to my professional role, my inherent core values, morals and professionalism.

How my clinical knowledge informed my observation and particularly noting what did not happen

The nature of the role of an Admiral Nurse/Dementia Clinical nurse specialist is a role to be proud of, a status that may be admired by others and comes with a degree of responsibility, accountability and moral virtues. Becoming emotionally invested in patients' lives and outcomes can be a difficult burden to carry, especially when research findings directly impact patient care and outcomes, and you may witness practice that challenges your core values.

Not actively participating in care was difficult, this was discussed during supervision and the challenges for me this may raise. Witnessing the distress of DSD, particularly when a patient was clinically unwell, challenged the practitioner/researcher role and led me to intervene in a call for help and to enable a staff member to care for the clinically unwell patient while I observed the patient with DSD walking in the corridor. It was during this time that I witnessed a note left at the patient's bedside, this had an emotional impact on me. An extract of the note below:

> "Keep fighting dad, we love you so much."

The impact of this brought me back to those early days of the pandemic, witnessing many patients with dementia and delirium with distressed reactions, witnessing the patient's sheer vulnerability and feeling a sense of not being able to deliver care within my professional role and thinking of my own dad.

More frequent were episodes when patients, their visitors or staff were wanting to engage in conversation about what I was doing, staff asked why I was not in uniform. During one period of observation, one patient described her experience of losing her husband, despite having delirium, this lady reflected on her life and the love lost, an example that patients with DSD still feel emotion and take comfort from relational caring. I found this episode extremely heart-warming and, despite knowing and reflecting upon the reason I was there, I was happy that I was able to provide comfort and was able to connect with the lady spiritually.

When scheduling care for people with DSD, what is accepted as good practice and how my observations demonstrated this did not happen can be explained by:

The allocation of resources (staff) to “levels” of need to patients with DSD was a challenge that I had anticipated to some extent. Some decisions that appeared to have been discussed among the MDT often were facilitated and interpreted by more junior staff depending on their workload and their understanding of delirium and the need for fundamentals of care to be met. The identification of those patients in need of close observation appeared to be directed to those with hyperactive delirium, meaning therefore those with hypoactive in need of care often went unrecognised. Therefore, when choosing where to place myself during the observation I did not rely solely on the handover alone, I used my judgement, experience and instinct a benefit of being a nurse researcher in the field. What was noticeable however, those staff providing enhanced care compared to observation being provided by Agency staff maintained a sense of security and provided support to other patients within the bay, the Agency staff reiterated that their role was to provide care for 1 patient, only seeing their job with the sole purpose of preventing harm to the patient in their care.

Reflecting on the above, I spoke to a colleague, nurse researcher within a similar field, discussing the barriers and facilitators of being a nurse and a researcher. I considered how my specialist clinical role may have the potential to cause bias, but I also reflected on the positive side to being an informed observer. I do this every day when going about my normal work routine when not undertaking research. My approach as a specialist practitioner and previously as a ward manager has always been to work alongside staff, to identify the good in people and practices and to celebrate this and share learning. Without my clinical experience, I would not have known about or picked up on those patients with hypoactive delirium, I may not have understood how to interpret distressed behaviours. I was mindful throughout every piece of observation that it was important to remember and record the good aspects of care, as that was the purpose of my research. I felt that I captured as many positives as possible that were presented during the observation. Reflecting on the dual role of researcher/practitioner and my everyday responsibility and accountability to keep the patient at the heart of everything I do, sometimes speaking up regarding concerns takes courage, can feel lonely and takes hard work to be alongside and encourage staff to see the best of a situation and to put themselves in the patients’ shoes.

I found the interviews easier to manage than the observations. I used the ethically approved interview schedule as a framework. Initially, on reflection the intention of this may have been because I considered the ethics approved interview guide as a safeguard to protect the research participant. I drew upon my experience as a mental health first aider, advanced skills in communication and skills in noticing distress rather than adopting a more academic style (Kvale, 2008). The importance of skilled facilitation in Appreciative Inquiry is well recognised (Dewar and MacBride, 2017, Edvardsson et al., 2014, Webster and Dewing, 2007), my interview style was positive and friendly. During the story telling approach, it was important that I listened to those stories that had been difficult for the participant ensuring I acknowledge them and was attentive to listening but, I believe, this led to building up a rapport, displaying empathy, not just the physical act but the spoken word was essential. AI also meant that collecting and validating positive participant stories and dream idea, promoted a relationship that evolved throughout the process. Ensuring I was using the 4D cycle, I was able to facilitate back. However, I combined the use of the semi-structured style interview guide with emotional touchpoints depending on the participant's ability to share their story. Combining the two at times proved difficult, some participants spoke freely, others benefited from the use of emotional touchpoints, the challenge was to ensure I was true to each individual style.

Emotional Intelligence

> *"Emotional intelligence in care is about the skill of intense listening, the ability to speak these emotions in self, sensitive emotional navigation with others - a desire to capture each person to be with you and to be with them*" (Professor David Sheard, 2024).

David Goleman, in his book Emotional Intelligence 1995, is accredited with the modern-day definition of emotional intelligence as:

> *the ability to perceive, use, understand and learn how to manage emotions" (Goleman, 1995)

These skills were fundamentally critical during the pandemic and going forward now within challenging times in the NHS. Many health and social care workers have had to draw on these innate skills, and the debate is whether they are part of our deep sense of self, personality and character or indeed whether these skills can be learnt. Sheard discusses emotional intelligence:

> “*emanates from a person when they have understood that all interactions have an emotional basis to them and when they are someone who navigates and processes a world of emotions in both a simple yet sophisticated manner”* (Sheard, 2022 pg. 26).

The whole movement of person-centred care was about challenging societal norms and disrupting a health and social care system that was, or is, not emotionally intelligent. Great strides have been made in the last 30 years embodying a philosophy of person-centred and relationship centred care focused care. However, this movement appears not to have addressed in equal measure the application of a person-centred philosophy to its workforce, as Cottam, 2021 summarises, “The COVID-19 pandemic has been a catalyst for exposing crisis in funding, culture and operation within our care system, suggesting the need for a new framework to enable new models of care to grow and thrive”. Cottam, 2021 suggests that the COVID-19 pandemic forced healthcare workers to “bum out, or numb out”, while for many staff this may resonate with them, in reality in clinical practice there are still many examples of compassionate, kind and dedicated staff who face adversity every day, but the little act of kindness or the little difference they make in what is often a challenging situation is what keeps them afloat.

Kitwood, 1997 drew on models of emotional intelligence from Rogers, 1961 in his philosophy of person-centred care when he stated that:

“contact should take us out of our customary patterns of overbusyness, hyper cognitivism and extreme talkatively into a way of being in which emotions and feelings are given a much larger place”.

Table 36: Charter of Emotional Intelligence (EI) in care - Sheard, 2022, pg.28

Emotions at work really matter to bring out the best in everyone
Making peoples’ diversity count is the heart of an emotionally intelligent
Organisations that create wellbeing thrive because of their emotional intelligence

Truth telling at work, requires an open, real, authentic culture or care
Individually being means embracing the whole of me in life at work
Opportunities for natural instincts to flourish leads to quality emotional care
Nurturing kindness is the foundation of developing people
Authenticity is the heart of being person-centred
Looking for organisational support in EI leads to a stringer work culture

Intelligence in care services ensures that peoples experience is essential
In
Calling out emotions at work requires courage
Always fighting for a feeling's philosophy is the core of real action on AI
Resilience in care means seeing strength in vulnerability
Ensuring we hold on to only being a flicker away from our own vulnerability creates person centred care

Emotional intelligence (EI) and emotional labour are closely connected in several ways. Emotional Intelligence refers to the ability to recognize, understand, manage, and effectively use emotions in ourselves and others. People with high EI are characteristically good at empathising with others, navigating social complexities, and managing their own emotions. Emotional Labour involves managing emotions and expressions as part of a professional role. It often requires workers to display certain emotions or suppress others to meet job expectations, especially in customer service, healthcare, and education.

Both EI and emotional labour involve managing one's own emotions. Emotional intelligence helps individuals handle emotional labour more effectively by providing tools to understand and regulate their feelings. High EI includes empathy, which is crucial for emotional labour. Being able to understand and respond to others' emotions makes the emotional labour required in jobs like nursing, teaching, and customer service more manageable and authentic. Emotional labour can be stressful because it involves hiding true feelings and maintaining a façade. Emotional intelligence provides strategies for managing this stress, such as recognizing when you're feeling overwhelmed and using coping mechanisms. Both EI and emotional labour improve interpersonal relationships. High EI helps in building rapport and maintaining positive interactions, which is a key component of emotional labour. High EI often leads to better job performance in roles requiring emotional labour because individuals can navigate complex emotional landscapes more skilfully. Understanding and developing emotional intelligence can make the demands of emotional labour less taxing and more fulfilling.

Rooney, 2019 in her thesis, A study of the importance of establishing a relationship between emotional intelligence and dementia care for the provision of PCC for home care workers established by understanding our emotions we better connect with others and highlighted the importance of establishing this in dementia care training. Sheard, 2015 suggested emotional intelligence is the key to good dementia care.

I have often considered and reflected upon this theory and in relation to working in a specialism such as dementia care and consider that emotional intelligence plays a significant role in dementia care. Working with individuals living with dementia requires patience, empathy and understanding, beyond just medical knowledge. I reflect on my early days as a qualified nurse, working on an older people's ward, a ward and a role that I loved. Many other professionals around me suggested I should move on from that role, go and embrace new learning, suggesting I would not learn anything if I stayed there; they couldn't have been more wrong. Although I did leave that ward, I went on to a career full of lifelong learning and loved what I did, and I believe having a high level of emotional intelligence has not only helped me to grow and develop, it has supported me to after 29 years be in a career and a role that I love and come to work every day with a passion to make a difference. Fostering key innate skills such as empathy, understanding and sharing feelings of those with dementia and their carers has helped me to develop trust and provide comfort. Introducing Namaste Care into the acute environment as a compassionate approach to care has provided me with a framework to role model and share best practice in dementia care, but most importantly getting staff to think differently about their approach. Having patience when the world around us is moving too fast, this is key in handling challenges without frustration. Having a higher level of EI has helped me to support family carers and staff to recognise non-verbal cues and respond appropriately, such as those fundamental human needs, enhancing the quality of interactions and providing interventions that are therapeutic. Being adaptable, recognising that every day can bring new challenges and being responsive to the changing needs of those with dementia is crucial. This resonates with me during my time managing an end-of-life care COVID-19 ward and a time when I got asked to take over a ward that required support, leaving my own ward behind. Having a strong AI helps with stress, recognising this in oneself is fundamental and will affect those who are giving and receiving care.

Emotional Labour

It was difficult to reconcile my values and beliefs as a practitioner with the need to be the observer documenting but not responding to patients' needs and care. Emotional challenges I faced were influenced by my professional role, and the role as a nurse researcher, and were compounded by clinical duties and the need to maintain a professional demeanour while managing my personal feelings. On reflection, I now recognise that increased access to support strategies and support systems to navigate these emotional demands would have been beneficial. The term emotional labour was first voiced by sociologist Arlie Hochschild in 1983 in her book, The Managed Heart. Hochschild, (1983) initially defined emotional labour as a workplace only circumstance, but over time, the concept has expanded to include the unpaid, often invisible work done by one person to meet the needs of another. At its simplest, it means managing your own feelings to present a work appropriate emotion. So, if you apply that concept to nursing, it means remaining calm and compassionate during difficult patient/family carer encounters, it means sitting with relatives when the patient is dying and trying to be in the moment with them, while perhaps relieving your loved one's bereavement, managing your own grief, suppressing your own grief, that is hard emotion work.

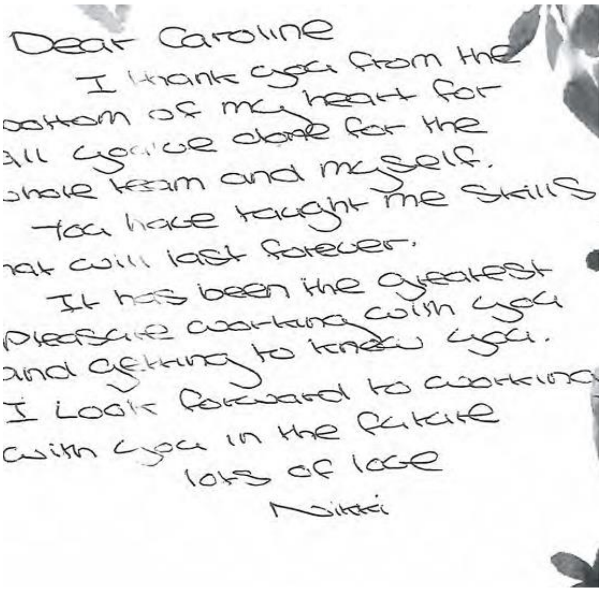
On another occasion, witnessing a patient with DSD being distressed for 19 minutes was difficult to witness, while the patient did not come to any physical harm, which is often what staff are most anxious about, her level of distress increased, it appeared as if she had not been heard.

Recognising the need to reflect on this and other examples, without disclosing patients' details, I spoke to a colleague with experience in research and a colleague who has an extensive background in staff/patient wellbeing. I understood it was important to manage my emotions and ensure as far as possible to keep those boundaries defined.

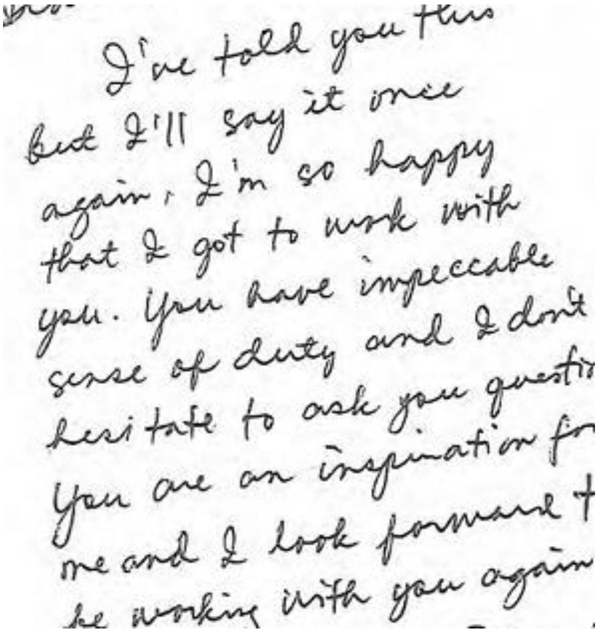
The emergence of COVID-19

COVID-19 brought upon us uncharted territory. I think back to March 2020, when while at work, I looked around me to see a sense of organised panic, expediting patients for discharge, huddles of senior staff in meetings and a sense of fear of the unknown. In those early days, information was slow in coming and we, as staff, learnt from each other, supported each other and grew in strength and camaraderie. I remember taking a call from my daughter, who worked in retail, who told me that the shop was closing, and they were being sent home; it felt like we were in our bubble in the hospital, yet the world outside was responding to uncertainty as well. I believed and, mostly, I felt lucky that life for me at work would continue, as a nurse with many years of experience in the NHS I would be expected to adapt to this crisis and support my colleagues.

I was approached by my line manager who asked that I come out of my role as a specialist nurse and set up and manage an end-of-life care COVID-19 ward. It was explained to me this would need to happen quickly; we were likely to see a lot of patients requiring end of life care and some with complex symptoms. With many years of ward management experience and a background in palliative care, this is something that I had the skills for but this situation I faced was one that I had never experienced before. I was concerned as to who would support my patient group that I cared for, especially as this time would be most challenging for them. I approached this with a sense of anxiety but felt extremely proud to be able to adapt, influence, lead and most proudly, I share extracts of ‘thank you’ from staff who worked alongside me…



Dear Caroline
I thank you from the
ottom of my heart for
ll you've done for the
hole team and myself.
You have taught me skills
at will last forever.
It has been the greatest
pleasure working with you
and getting to know you.
I look forward to working
with you in the future
lots of love
Nikki



I've told you this
but I'll say it once
again, I'm so happy
that I got to work with
you. You have impeccable
sense of duty and I don't
hesitate to ask you questi
You are an inspiration fo
me and I look forward t
be working with you again

In terms of university work, I had an abundance of work to get through which just needed time. Considering how other colleagues undertaking Doctorate research who were not patient facing crossed my mind, comparing my progress with theirs, wondering if they would be using this time fruitfully.

The challenges of lockdown for me in comparison to how patients with Dementia and delirium experience were little in comparison. I was able to use this time, when not at work, to focus on university work, keeping in contact with my supervisors, having this work to focus on helped me in some ways get through the difficult time, I thank them for their support.

Imposter syndrome has visited me throughout my journey. Imposter syndrome, a phenomenon, has received a lot of attention within academic literature (e.g. Clance & Imes, 1978; Chapman, 2017; Handforth, 2022; Langford & Clance, 1993). Characterised by an incapability to attribute one's own successes and achievements to their selves, often doubting your abilities and the fear of being exposed as a fraud, “imposter” and believe that others overestimate their competence. Despite contact with supervisors, and reassurance from close colleagues connecting and networking with other students, did not seem a priority when we were faced with so many other challenges; so often these feelings were kept within. A recommendation for other colleagues going through this process is the importance of peer support and making sure we take time to access this; I reflect on feeling alone at times during my studies and sharing experiences is crucial to, not only your own growth and development, but that emotional and practical support from each other is fundamental. Juggling a busy job in the NHS, home life and University work is tough, often if felt one area was being neglected for another. What kept me motivated and determined was the difference, I hope, this research makes for future staff who care for patients with DSD and the impact of this knowledge on the experience both patients and families receive.

During initial phases of COVID-19 and redeployment to a different role, I was exposed to an experience like many of my colleagues that is hard to quantify and one that we hope never to have to face again. During this time, I witnessed many patients with dementia with such significant distress and delirium, particularly at the end of the lives. I witnessed patients with dementia isolated from families. My own father-in-law, who lived and died with Alzheimer's Dementia, was admitted following a hip fracture and I was advised not to visit him, to follow the rules. We were informed that we should provide as minimal contact as we could after delivering the required care for our patients. Yet we know, it is born in us to hug people, nurture, reassure and provide comfort when someone is distressed. Not being able to do that for many of us took its toll, particularly on our patients with dementia and their families. My work will continue to drive forward the message to staff of the importance of displaying empathy, taught within Sage and Thyme, now mandatory foundation level communication skills for nurses, Health Care Support Workers (HCSW) and Allied Health Professionals (AHP). I provided a communication link to families that could not visit. How I managed this, the ability to support such distress and coping strategies to provide care in a relationship centred way, was integral to providing reassurance for the family carer, comfort for the patient and an internal peace for myself as a practitioner.

I have learnt a lot about myself along this journey, I reflect on what I may have been able to do differently in terms of my studies, but I am proud of myself for my strength to keep going, to get through a difficult time at work and to always keep the reason I undertook this study and the patient and their family carer at the heart of everything I do. COVID-19 has not changed me, I still come to work every day with a passion to make a difference, if anything, it has provided me with the emotional intelligence to really see deeply into the lives of people with DSD and making a difference in their care and supporting staff to understand how to care for them is unmeasurable.

My motivation to explore this area of dementia care comes from knowing how underreported DSD is in clinical practice and witnessing every day the outcome often of DSD such as patients who may have an extended length of stay increased risk of falls, deconditioning, aspiration and mortality. My motivation also comes from a personal experience of caring for my Dad, who did not have dementia, but 22 years ago died with cancer and had terminal delirium at the end of his life. The experience was traumatic, and one that even staff in a hospice setting did not truly understand. To understand what the barriers are to supporting family carers and improving those relationships to enhance patient care and care experience is fundamental. The findings present opportunities to examine areas of good practice and how we may integrate these into future learning and care but also highlight just how much more we need to do. I cannot overestimate the importance for me to complete this study and to share my experience, through learning, sharing knowledge with others particularly through case study and simulation techniques.

Conclusion

This study has tackled an area of nursing care that is largely overlooked and misunderstood with the routine care of patients with dementia. It has highlighted the need for staff to understand how to avoid hospital incidence of delirium, the recognition of signs and symptoms of DSD and the tension between what is important for the individual and how that is approached within the day-to-day culture and running of the ward. Key findings address the importance of involving staff who work closely with patients in staff-to-staff conversations and review, and the benefits of recognising examples of good practice to support learning and appreciation of what matters to patients and their family carers.

Future work should address how to reconcile environments, priorities and staff pressures that do not always support staff to deliver care they know is person centred and family aware.

References

Abbey, J., Piller, N., Bellis, A. D., Esterman, A., Parker, D., Giles, L., & Lowcay, B. (2004). The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. *International journal of palliative nursing*, *10*(1), 6-13.

Abbott, R., Rogers, M., Lourida, L., Green,C., Ball, S., Hemsley,A., Cheesman, D., Clare, L., Moore,D., Hussey, C., Coxon, G., Llewellyn, D, J., Naldrett, T., & Thompson Coon, J (2022). New horizons for caring for people with dementia in hospital: the DEMENTIA CARE pointers for service change. *Age and Ageing, 51*(9), afac190. https://doi.org/10.1093/ageing/afac190

Abma, T. A., & Widdershoven, G. A. M. (2005). Sharing stories: Narrative and dialogue in responsive nursing evaluation. *Evaluation & the health professions, 28*(1), 90-109. https://doi.org/10.1177/0163278704273080

Abraha, I., Trotta, F., Rimland, J. M., Cruz-Jentoft, A., Lozano-Montoya, I., Soiza, R. L., Pierini, V., Fulgheri, P.D., Lattanzio, F., O'Mahony, D., & Cherubini, A. (2015). Efficacy of non-pharmacological interventions to prevent and treat delirium in older patients: a systematic overview. The SENATOR project ONTOP series. *PloS one*, *10(*6), e0123090.

Adamis, D., Treloar, A., Martin, F. C., & Macdonald, A. J. (2007). A brief review of the history of delirium as a mental disorder. *History of Psychiatry*, *18*(4), 459-469.

Adams, C. D. (1868) *The genuine works of Hippocrates.* New York: Dover. Available at: https://www.perseus.tufts.edu/hopper/text?doc=Perseus%3Atext%3A1999.01.0248%3Atext%3DAph.%3Achapter%3D2 (Accessed: 01 May 2025).

Adams T, & Gardiner P. (2005). Communication and interaction within dementia care triads: developing a theory for relationship-centred care. *Dementia*, *4*(2), 185–205.

Alzheimer's Disease International. (2021). *World Alzheimer Report*: *Journey through the diagnosis of dementia*. Retrieved from, https://www.alzint.org/resource/world-alzheimer-report-2021/

Alzheimer's Research UK. (2023). *What is Alzheimers Disease.* Retrieved from https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/alzheimers-disease/

Alzheimer's Research UK. (n.d.) *Facts and Stats*. Retrieved from https://www.alzheimersresearchuk.org/dementia-information/need-to-know-more/facts-stats/

Alzheimer’s Society. (2016 January). *Fix Dementia Care Hospitals*. London: Alzheimer’s Society [online], Available from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_-_hospitals.pdf

Alzheimer's Society. (2019). *What are the costs of dementia care in the UK?* Retrieved 03 March 2023, from https://www.alzheimers.org.uk/blog/how-much-does-dementia-care-cost

Alzheimer’s Society. (2020). *Alzheimer’s Society analysis of NHS England’s Hospital Episode Statistics dataset 2012/13 to 2017/18*. Retrieved from https://www.alzheimers.org.uk/sites/default/files/2020-01/Hospital%20Admissions%202012-18%20for%20people%20with%20dementia%20Alzheimer%27s%20Society%202020.pdf

Alzheimer’s Society. (2021). *Relationships and Dementia*. Retrieved from http// alzheimers.org.uk/get-support/daily-living/relationships-dementia

Alzheimer’s Society. (2022). *Maintaining your relationship after a dementia diagnosis*. Retrieved from http//alzheimers.org.uk/get-support/daily-living/maintaining-relationships-dementia

Amador, S., Goodman, C., King, D., Ng, Y. T., Elmore, N., Mathie, E., Machen, I & Knapp, M. (2014). Exploring resource use and associated costs in end-of-life care for older people with dementia in residential care homes. *International Journal of Geriatric Psychiatry*, *29*(7), 758-766.

Anantapong, K., Davies, N., Sampson, E, L. (2022). Communication between the multidisciplinary team and families regarding nutrition and hydration for people with severe dementia in acute hospitals: a qualitative study. *Age and Ageing*, *51*(11), 1-10.

Anderson, H. (1997). *Conversation, language, and possibilities: A postmodern approach to therapy*. Basic Books.

Anderson, D. (2005). Preventing delirium in older people. *British Medical Bulletin, 73*(1), 25-34.

Apold, S. (2018). Delirium superimposed on dementia. *The Journal for Nurse Practitioners*, *14*(3), 183-189.

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, *8*(1), 19-32.

Ashton, C., & Manthorpe, J. (2019). The views of domestic staff and porters when supporting patients with dementia in the acute hospital: an exploratory qualitative study. *Dementia*, *18*(3), 1128-1145.

Astell, A., Alm, N., Gowans, G., Ellis, M., Dye, R., & Vaughan, P. (2009). Involving older people with dementia and their carers in designing computer based support systems: some methodological considerations. *Universal Access in the Information Society*, *8*, 49-58.

Australian Institute of Health and Welfare. (2013). *Dementia care in hospitals: costs and strategies* (AGE 72). https://www.aihw.gov.au/getmedia/9c7deaeb-1b8c-4e40-8763-cc01560642cc/14347_20130502.pdf.aspx

Avelino-Silva, T. J., Campora, F., Curiati, J. A., & Jacob-Filho, W. (2017). Association between delirium superimposed on dementia and mortality in hospitalized older adults: A prospective cohort study. *PLoS Medicine*, *14*(3), e1002264.

Ayton, D., Moran, C., Berkovic, D., Bateman, C., Anderson, K., Blair, A., Soh, S. E., Morello, R., Lim, Y. Y., & Liew, D. (2020). The Volunteer Dementia and Delirium Care (VDDC): A pre-implementation study exploring perceived acceptability to implementing the program in an acute and subacute metropolitan hospital. *Australasian Journal on Ageing, 39*(3), e322-e333.

Bamforth, K., Rae, P., Maben, J., Lloyd, H., & Pearce, S. (2023). Perceptions of healthcare professionals' psychological wellbeing at work and the link to patients' experiences of care: A scoping review. *International Journal of Nursing Studies Advances*, *5*, 100148.

Banerjee, S., Farina, N., Daley, S., Grosvenor, W., Hughes, L., Hebditch, M., ... & Wright, J. (2017). How do we enhance undergraduate healthcare education in dementia? A review of the role of innovative approaches and development of the Time for Dementia Programme. *International journal of geriatric psychiatry*, *32*(1), 68-75.

Banovic, S., Zunic, L. J., & Sinanovic, O. (2018). Communication difficulties as a result of dementia. *Materia Socio-Medica*, *30*(3), 221.

Bate P, Robert G. (2007). *Bringing user experience to healthcare improvement: the concepts, methods and practices of experience based design*. Radcliffe Publishing.

Bate, P. A. U. L., Mendel, P., & Robert, G. (2008). Organizational and professional identity: Crisis, tradition and quality at the Royal Devon and Exeter NHS Foundation Trust. In *Organizing for quality: The improvement journeys of leading hospitals in Europe and the United States*. Radcliffe Publishing.

Bate, S. P., & Robert, G. (2009). Bringing social movement theory to healthcare practice in the English National Health Service. In J. Banaszak-Holl, S.R. Levitsky & M. Zald (eds). (2009). *Social movements and the transformation of American health care* (section 12). Oxford University Press.

Bateman, C., Anderson, K., Bird, M., & Hungerford, C. (2016). Volunteers improving person-centred dementia and delirium care in a rural Australian hospital. *Rural and Remote Health. 16*(2), 3667.

Beach MC, Inui T. (2006). Relationship-Centered Care Research Network. Relationship-centered care: A constructive reframing. *Journal of General Internal Medicine, 21*(Supplement 1), S3–S8.

Beauchamp, Tom L., and James F Childress. 2013. Principles of Biomedical Ethics. Seventh Edition ed. USA: Oxford University Press.

Beck, A. T. (1976). Cognitive therapy and the emotional disorders, 356. International Universities Press.

Benner, P., Tanner, C. A., & Chesla, C. A. (Eds.). (2009). *Expertise in nursing practice: Caring, clinical judgment, and ethics*. Springer Publishing Company.

Bergum, V., & Dossetor, J. B. (2005). *Relational ethics: The full meaning of respect* (pp. 165-196). University Publishing Group.

Berrios, G. E. (1981). Delirium and confusion in the 19th century: a conceptual history. *The British Journal of Psychiatry*, *139*(5), 439-449.

Bethell, J., Commisso, E., Rostad, H. M., Puts, M., Babineau, J., Grinbergs-Saull, A., Wighton, M.B., Hammel, J., Doyle, E., Nadeau, S., & McGilton, K. S. (2018). Patient engagement in research related to dementia: a scoping review. *Dementia*, *17*(8), 944-975.

Bianchetti, A., Rozzini, R., Bianchetti, L., Coccia, F., Guerini, F., & Trabucchi, M. (2022). Dementia Clinical Care in Relation to COVID-19. *Current Treatment Options in Neurology*, 1-15.

Bickford, B., Daley, S., Sleater, G., Hebditch, M., & Banerjee, S. (2019). Understanding compassion for people with dementia in medical and nursing students. *BMC Medical Education*, *19*, 35 1-8.https://doi.org/10.1186/s12909019-1460-y

Birkenhäger-Gillesse, E. G., Achterberg, W. P., Janus, S. I. M., Kollen, B. J., & Zuidema, S. U. (2020). Effects of caregiver dementia training in caregiver-patient dyads: A randomized controlled study. *International Journal of Geriatric Psychiatry, 35*(11), 1376-1384. https://www.doi.org/10.1002/gps.5378

Birkenhäger-Gillesse, E. G., Achterberg, W. P., Janus, S. I., Zuidema, S. U., & van den Hout, W. B. (2022). Cost-effectiveness of dementia training for caregivers in caregiver-patient dyads: A randomized controlled study. *Alzheimer's & Dementia: Translational Research & Clinical Interventions, 8*(1), e12281.

Blair, A., Anderson, K., & Bateman, C. (2018). The “Golden Angels”: effects of trained volunteers on specialling and readmission rates for people with dementia and delirium in rural hospitals. *International psychogeriatrics, 30*(11), 1707-1716. http://www.doi.org/10.1017/S1041610218000911

Bolles S, Maley M. (2004). Designing relational models of collaborative integrative medicine that support healing processes. *Journal of Alternative & Complementary Medicine*. *10* (Supplement 1), S61–S69.

Boltz, M., Capezuti, E., Bowar-Ferres, S., Norman, R., Secic, M., Kim, H., Fairchild, S., Mezey, M., & Fulmer, T. (2008). Hospital Nurses' Perception of the Geriatric Nurse Practice Environment. *Journal of Nursing Scholarship, 40*(3), 282-289. https://doi.org/10.1111/j.1547-5069.2008.00239

Boltz, M., Chippendale, T., Resnick, B., & Galvin, J. E. (2015). Testing family-centered, function-focused care in hospitalized persons with dementia. *Neurodegenerative Disease Management, 5*(3), 203-215.

Boltz, M., Kuzmik, A., & Rose, K. (2023). Improving hospital and post-acute outcomes and experiences of dyads living with dementia: results of the fam-ffc trial. *Innovation in Aging*, *7*(Supplement 1), 93-93.

Bommarito, G., Garibotto, V., Frisoni, G. B., Assal, F., Lalive, P. H., & Allali, G. (2022). The two-way route between delirium disorder and dementia: insights from COVID-19. *Neurodegenerative Diseases*, *22*(3-4), 91-103.

Borkan, J. (1999). Immersion/crystallization. In Crabtree, B.F., & Miller, W.L. (eds). *Doing qualitative research*, 2nd ed. Sage, pp.179-194.

Borson S., Scanlan, J., Brush, M., Vitaliano, P., & Dokmak, A. (2000).The mini-cog: a cognitive vital signs measure for dementia screening in multi-lingual elderly. *International Journal of Geriatric Psychiatry*. *15*(11), 1021. https://doi.org/10.1002/1099-1166(200011)15:11%3C1021::AID-GPS234%3E3.0.CO;2-6

Bourgeois, M. S. (2019). Caregiving for persons with dementia: Evidence-based resources for SLPs. *Topics in Language Disorders*, *39*(1), 89-103.

Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & Society*, *29*(7), 1130-1144.

Bradbury-Jones. C (2007). Enhancing rigour in qualitative health research. Exploring subjectivity through Peshkin's I's *Journal of Advanced Nursing*. *59*(3), 290-298. http://doi.org/20.1111/j.1365-2648.2007.04306.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. *3*, 77-101.

Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*. *9*(1), 26152.

Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: a dyadic perspective. *Aging and Mental Health*, *13*(3), 426-436.

Bridges, J., Nicholson, C., Maben, J., Pope, C., Flatley, M., Wilkinson, C., Meyer, J., & Tziggili, M. (2013). Capacity for care: meta-ethnography of acute care nurses' experiences of the nurse-patient relationship. *Journal of advanced Nursing*, *69*(4), 760-772.

Briggs, R., Coary, R., Collins, R., Coughlan, T., O'Neill, D., & Kennelly, S. P. (2016). Acute hospital care: how much activity is attributable to caring for patients with dementia? *QJM: An international Journal of Medicine, 109*(1), 41-44. https://doi.org/10.1093/qjmed/hcv085

British Geriatric Society. (2020). *Coronavirus: Managing delirium in confirmed and suspected cases.* Retrieved from www.bgs.org.uk/resources/coronavirus-managing-delirium-in-confirmed-and-suspected-cases?UID=866138019202512121450

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in clinical neuroscience*, *11*(2), 217-228.

Brooke, J., Cronin, C., Stiell, M., & Ojo, O. (2018). The intersection of culture in the provision of dementia care: A systematic review. *Journal of Clinical Nursing*, *27*(17-18), 3241-3253.

Brooke, J., & Ojo, O. (2018). Elements of a sustainable, competent, and empathetic workforce to support patients with dementia during an acute hospital stay: a comprehensive literature review. *The International journal of health planning and management*, *33*(1), e10-e25.

Brooker, D., Foster, N., Banner, A., Payne, M., & Jackson, L. (1998). *The efficacy of Dementia Care Mapping as an audit tool: Report of a 3-year British NHS evaluation.* Taylor & Francis.

Brooker, D. (2004). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, *13*, 215-222.

Brooker, D., & Latham, I. (2015). *Person-centred dementia care: Making services better with the VIPS framework*. Jessica Kingsley Publishers.

Brossard Saxell, T., Ingvert, M., & Lethin, C. (2021). Facilitators for person-centred care of inpatients with dementia: A meta-synthesis of registered nurses' experiences. *Dementia*, *20*(1), 188-212.

Brown, J., Bowling, A. & Flynn, T. Models of quality of life: A taxonomy, overview and systematic review of the literature. (2004). European Forum on Population Ageing Research.

Buchan, J., & Catton, H. (2023). *Recover to rebuild. Investing in the nursing workforce for health system effectiveness.* International Council of Nurses.

Buckley, W. (1967). *Sociology and Modern Systems Theory*. Prentice-Hall.

Buckley, W. (1968). Society as a complex adaptive system. In Buckley W, editor. *Modern Systems Research for the Behavioral Scientist.* Aldine.

Bunn, F., Burn, A. M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., & Brayne, C. (2014). Comorbidity and dementia: a scoping review of the literature. *BMC medicine*, *12*, 1-15.

Bunn, F., Lynch, J., Goodman, C., Sharpe, R., Walshe, C., Preston, N., & Froggatt, K. (2018). Improving living and dying for people with advanced dementia living in care homes: a realist review of Namaste care and other multisensory interventions. *Bmc Geriatrics*, *18*, 1-15.

Bushe, G. R. (2010). A comparative case study of appreciative inquiries in one organization: implications for practice. *Revista de Cercetare si Interventie Sociala*, *29*(7), 7-24.

Bushe, G. R. (2011). Appreciative Inquiry: theory and critique. In: Boje, D., Burnes, B., & Hassard, J. (ed.) *The Routledge companion to organizational change*. Routledge.

Cadman, C., & Brewer, J. (2001). Emotional intelligence: a vital prerequisite for recruitment in nursing. *Journal of nursing management*, *9*(6), 321-324.

Calsolaro, V., Femminella, G. D., Rogani, S., Esposito, S., Franchi, R., Okoye, C., Rengo, G., & Monzani, F. (2021). Behavioral and psychological symptoms in dementia (BPSD) and the use of antipsychotics. *Pharmaceuticals*, *14*(3), 246.

Cameron, K. S., Dutton, J. E., & Quinn, R. E. (2003). An introduction to positive organizational scholarship. *Positive Organizational Scholarship*, *3*(13), 2-21.

Canadian Association of Schools of Nursing (2014) National Nursing Education Summit Summary Report. Retrieved from: tinyurl.com/canada-nursingsummit (Last accessed 25th February 2025).

Caplan, G. A., Teodorczuk, A., Streatfeild, J., & Agar, M. R. (2020). The financial and social costs of delirium. *European Geriatric Medicine*, *11*, 105-112.

Caraceni, A., & Grassi, L. (2011). *Delirium: acute confusional states in palliative medicine*. Oxford University Press, USA.

Carbone, M. K., & Gugliucci, M. R. (2015). Delirium and the family caregiver: the need for evidence-based education interventions. *The Gerontologist*, *55*(3), 345-352.

Carparelli, C., Jones, C., Oyebode, J. R., & Riley, G. A. (2024). A systematic review of the effectiveness of educational interventions in promoting person-centred care in dementia services. *Clinical gerontologist*, *47*(5), 665-683.

Casarez, A., & Smith, J. G. (2024). Associations between hospital organizational features, person-centred care and nurse-sensitive outcomes for persons with dementia in acute care: A systematic literature review. *Journal of Advanced Nursing*, *80*(10), 3915-3936.

Cerejeira, J., & Mukaetova-Ladinska, E. B. (2011). A clinical update on delirium: from early recognition to effective management. *Nursing Research and Practice*, *2011*(1), 1-12. https://doi.org/10.1155/2011/875196

Chapman, A. (2017). Using the assessment process to overcome Imposter Syndrome in mature students. *Journal of Further and Higher Education*, *41*(2), 112-119.

Cheong, C. Y., Tan, J. A. Q., Foong, Y. L., Koh, H. M., Chen, D. Z. Y., Tan, J. J. C., Ng, C.J., & Yap, P. (2016). Creative music therapy in an acute care setting for older patients with delirium and dementia. *Dementia and Geriatric Cognitive Disorders Extra*, *6*(2), 268-275.

Chew, E. Y. H., Ong, Z. L., Glass Jr, G. F., & Chan, E. Y. (2022). ‘24/7’ Caregiving: A Qualitative Analysis of an Emerging Phenomenon of Interest in Caregiving. *International Journal of Environmental Research and Public Health*, *19*(24), 17046.

Chien, L. J., Slade, D., Dahm, M. R., Brady, B., Roberts, E., Goncharov, L., Taylor, J., Eggins, S., & Thornton, A. (2022). Improving patient-centred care through a tailored intervention addressing nursing clinical handover communication in its organizational and cultural context. Journal of Advanced Nursing, 78(5), 1413–1430. https://doi.org/10.1111/jan.15110

Clance, P. R., & Imes, S. A. (1978). The imposter phenomenon in high achieving women: Dynamics and therapeutic intervention. *Psychotherapy: Theory, Research & Practice*, *15*(3), 241.

Cloak N, Schoo C, Al Khalili Y. Behavioral and Psychological Symptoms in Dementia. 2024 Feb 27. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan–. PMID: 31855379.

Clissett, P., Porock, D., Harwood, R. H., & Gladman, J. R. (2013). The challenges of achieving person-centred care in acute hospitals: a qualitative study of people with dementia and their families. *International journal of nursing studies*, *50*(11), 1495-1503.

Clouder, L., & King, V. (2015). *What works? A critique of appreciative inquiry as a research method/ology. Theory and method in higher education research*. Emerald Group Publishing Limited.

Coban, G. I., Kiirca, N., & Yurttas, A. (2015). Analysis of nurses' attitudes about the nursing profession in southern Turkey. *International Journal of Caring Sciences*, *8*(3), 665.

Cohen-Mansfield, J. (2000). Theoretical frameworks for behavioral problems in dementia. *Alzheimer's Care Today*, *1*(4), 8-21.

Cohen-Mansfield, J. (2001). Nonpharmacologic interventions for inappropriate behaviors in dementia: a review, summary, and critique. *The American Journal of Geriatric Psychiatry*, *9*(4), 361-381.

Collier, A., De Bellis, A., Hosie, A., Dadich, A., Symonds, T., Prendergast, J. Rodrigues, J., & Bevan, A. (2020). Fundamental care for people with cognitive impairment in the hospital setting: A study combining positive organisational scholarship and video-reflexive ethnography. *Journal of Clinical Nursing, 29*(11-12), 1957-1967.

Connors, M. H., Seeher, K., Teixeira-Pinto, A., Woodward, M., Ames, D., & Brodaty, H. (2020). Dementia and caregiver burden: a three-year longitudinal study. *International journal of geriatric psychiatry*, *35*(2), 250-258.

Cooper L, Beach M, Johnson R, Inui T. (2006). Delving below the surface: understanding how race and ethnicity influence relationships in healthcare. *Journal of General Internal Medicine*, *21*(Supplement 1), S21–S27.

Cooper, R. A., & Pitts, M. J. (2022). Caregiving spouses' experiences of relational uncertainty and partner influence in the prolonged relational transition of Alzheimer's disease and related dementias. *Journal of Social and Personal Relationships*, *39*(5), 1434-1459.

Cooperrider, D. L., Barrett, F., & Srivastva, S. (1995). Social construction and appreciative inquiry: A journey in organizational theory. In D. Hosking, H. Peter Dachler, K. Gergen (eds.). *Management and Organization: Relational Alternatives to Individualism*, pp.157-200.

Cooperrider, D. L., & Whitney, D. (2001). A positive revolution in change: Appreciative inquiry. *Public Administration and Public Policy, 87*, 611-630.

Cooperrider, D. L., Whitney, D., & Stavros, J. M. (2003). *Appreciative inquiry handbook: The first in a series of AI workbooks for leaders of change* (Vol. 1). Berrett-Koehler Publishers.

Cooperrider, D., & Whitney, D. D. 2005. Appreciative inquiry: A positive revolution in change, Berrett-Koehler Publishers, Oakland, CA.

Cooperrider, D. L., Sekerka, L. E., & Sekerka, L. (2003a). Inquiry into the appreciable world: Toward a theory of positive organziational change. *Positive Organizational Scholars*, 225-240.

Cooperrider, D. L., & Srivastva, S. (1987). Appreciative inquiry in organizational life. *Research in Organizational Change and Development, 1*, 129-169.

Cooperrider, D. L., & Srivastva, S. (2013). A Contemporary Commentary on Appreciative Inquiry in Organizational LifeAppreciative Inquiry in Organizational Life☆ Cooperrider, D. and Srivastva, S.(1987). Appreciative inquiry in organizational life. In R. Woodman and W. Pasmore (Eds.), Research in organizational change and development, Vol. 1, pp. 129–169. In *Organizational generativity: The appreciative inquiry summit and a scholarship of transformation* (Vol. 4, pp. 3-67). Emerald Group Publishing Limited.

Cooperrider, D., Whitney, D. D., Stavros, J. M., & Stavros, J. (2008). *The appreciative inquiry handbook: For leaders of change*, Berrett-Koehler Publishers.

Cooperrider, D. L., Whitney, D. K., & Stavros, J. M. (2003b). *Appreciative Inquiry Handbook*. Berrett-Koehler Publishers.

Cooperrider, D. L., Whitney, D., & Stavros, J. M. (2003). *Appreciative inquiry handbook: The first in a series of AI workbooks for leaders of change* (Vol. 1). Berrett-Koehler Publishers.

Costello, J. (2001). Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *Journal of advanced nursing*, *35*(1), 59-68.

Cottam, H. (2021) *A raducak new vision for social care: how to reimagine and redesign support systens for this century.* London: The Health Foundation

COOPERRIDER, D. & WHITNEY, D. D. 2005. Appreciative inquiry: A positive revolution in change, Berrett-Koehler Publishers, Oakland, CA.

Cooperrider, D. L., Whitney, D., & Stavros, J. M. (2003). *Appreciative inquiry handbook: The first in a series of AI workbooks for leaders of change* (Vol. 1). Berrett-Koehler Publishers.

COOPERRIDER, D., WHITNEY, D. D., STAVROS, J. M. & STAVROS, J. 2008. The appreciative inquiry handbook: For leaders of change, Berrett-Koehler Publishers.

COOPERRIDER, D. L., BARRETT, F. & SRIVASTVA, S. 1995. Social construction and appreciative inquiry: A journey in organizational theory. Management and Organization: Relational Alternatives to Individualism, 157-200.

COOPERRIDER, D. L., SEKERKA, L. E. & SEKERKA, L. 2003a. Inquiry into the appreciable world: Toward a theory of positive organziational change. Positive Organizational Scholars, 225-240.

COOPERRIDER, D. L. & SRIVASTVA, S. 1987. Appreciative inquiry in organizational life. Research in organizational change and development, 1, 129-169.

Cooperrider, D. L., & Srivastva, S. (2013). A Contemporary Commentary on Appreciative Inquiry in Organizational Life Appreciative Inquiry in Organizational Life☆

COOPERRIDER, D. L. & WHITNEY, D. 2001. A positive revolution in change: Appreciative inquiry. Public administration and public policy, 87, 611-630.

.

COOPERRIDER, D. L., WHITNEY, D. K. & STAVROS, J. M. 2003b. Appreciative Inquiry Handbook, Berrett-Koehler Publishers, Oakland, CA.

Conneeley, A, L (2002). Methodological issues in qualitative research for the research/practitioner. *British Journal of Occupational Therapy*, *65*(4), 185-190.

Costello, J. (2001). Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *Journal of advanced nursing*, *35*(1), 59-68.

Cottam, H. (2021) *A raducak new vision for social care: how to reimagine and redesign support systens for this century.* London: The Health Foundation

Coyle, M. A., Burns, P., & Traynor, V. (2017). Is it my job? The role of RNs in the assessment and identification of delirium in hospitalized older adults: An exploratory qualitative study. *Journal of gerontological nursing*, *43*(4), 29-37.

Crandall, A., Daines, C., Barnes, M. D., Hanson, C. L., & Cottam, M. (2021). Family well-being and individual mental health in the early stages of COVID-19. *Families, Systems, & Health*, *39*(3), 454.

Crocker, E., Beggs, T., Hassan, A., Denault, A., Lamarche, Y., Bagshaw, S., Elmi-Sarabi, M., Hiebert, B., MacDonald, K., Giles-Smith, L., Tangri, N., & Arora, R.

C. (2016). Long-term effects of postoperative delirium in patients undergoing cardiac operation: a systematic review. *The Annals of thoracic surgery*, *102*(4), 1391-1399.

Crowther, G. J. E., Bennett, M. I., & Holmes, J. D. (2017). How well are the diagnosis and symptoms of dementia recorded in older patients admitted to hospital? *Age and ageing, 46*(1), 112-118. https://doi:10.1093/ageing/afw169

Cunningham C, Macfarlane S, Brodaty H. (2019). Language paradigms when behaviour changes with dementia: #BanBPSD. *International Journal of Geriatric Psychiatry*, *34*(8), 1109-1113. https://doi.org/10.1002/gps.5122

Danziger, K. (1997). The varieties of social construction: Essay review. Theory and Psychology, 7 (3),399–416.

Davies,N., Maio,L., Rait,G., Iliffe,S. (2014). What have family carers told us so far ? A narrative synthesis. *Palliative Medicine, 28*(7), 919-930.

Davis, D., Searle, S. D., & Tsui, A. (2019). The Scottish Intercollegiate Guidelines Network: risk reduction and management of delirium. *Age and Ageing*, *48*(4), 485-488.

De Lange, S., Heyns, T., & Filmalter, C. (2024). Reaching consensus on the definition of person-centred handover practices in emergency departments: A modified online Delphi. *Journal of Clinical Nursing*, *33*(5), 1751-1761.

Department of Constitutional Affairs. (2007). *Mental Capacity Act 2005; code of practice*. Retrieved 09 March, 2022, from https://www.gov.uk/government/publications/mental capacity-act-code-of-practice

Department of Health (2006). *Best Research for Best Health: A New National Health Research Strategy. Retrieved 20 July, 2021 from* https://www.gov.uk/government/publications/best research-for-best-health-a-new-national-health-research-strategy

Department of Health (2006). Best Research for Best Health: A New National Health Research Strategy In: HEALTH, D. O. (ed.). London: HMSO. new-national-health-research-strategy. [Accessed 20/07/2021]

Department of Health. (2008). *Guidance on nominating a consultee for research involving adults who lack capacity to consent*. Retrieved 01 December, 2022 from https://www.hra.nhs.uk/planning-and-improving-research/policies-standards legislation/mental-capacity-act/

Department of Health. (2009). *Living well with Dementia: A National Dementia Strategy.* Retrieved from https//assets publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

Department of Health. (2015). *Prime Minister's challenge on dementia 2020*. Retrieved 29 November, 2024 from http://www.go.uk/government/publications/prime-ministers-challenge-on-dementia

Department of Health. (2020). *Prime Ministers challenge on dementia 2020.* Retrieved 04 January, 2025 from http://www.go.uk/government/publications/prime-ministers-challenge-on-dementia-2020/b7c2cc6a-5239-40eb-bc72-7b408b5df846

Department of Health & Social Care. (2022). A plan for digital health and social care. https://www.gov.uk/government/publications/a-plan-for-digital-health-and-social-care/a-plan-for-digital-health-and-social-care

Dewar, B. (2010). Editorial: Appreciative Inquiry, *International Journal of Older People Nursing*. *5*(4), 290-291.

Dewar, B., Mackay, R., Smith, S., Pullin, S., & Tocher, R. (2010). Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting. *Journal of Research in Nursing*, *15*(1), 29-41.

Dewar, B. (2011). *Caring about caring: An appreciative inquiry about compassionate relationship centred care* [Doctoral dissertation, Edinburgh Napier University]. Edinburgh Napier University. https://napier-repository.worktribe.com/output/196625

Dewar, B., Pullin, S., & Tocheris, R. (2011). Valuing compassion through definition and measurement. *Nursing Management*, *17*(9), 32-37.

Dewar, B. (2012). Using creative methods in practice development to understand and develop compassionate care. *International Practice Development Journal*, *2*(1), 1-11.

Dewar B., & Nolan, M. (2013). Caring about caring: developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, *50*(9), 1247–1258.

Dewar, B., & MacBride, T. (2017). Developing caring conversations in care homes: An appreciative inquiry. *Health & social care in the community*, *25*(4), 1375-1386.

Dewing, J. (2002). From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, *1*(2), 157-171.

Dewing, J. (2004). Concerns relating to the application of frameworks to promote person-centredness in nursing with older people. *International Journal of Older People Nursing*, 13(3a), 39-44.

Dewing, J. (2007). Participatory research: a method for process consent with persons who have dementia. *Dementia*, *6*(1), 11-25.

Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics Review*, 4, 59-64.

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: what challenges do qualitative researchers face?. *Qualitative research*, *7*(3), 327-353.

Di Lorito, C., Godfrey, M., Dunlop, M., Bosco, A., Pollock, K., van der Wardt, V., & Harwood, R. H. (2020). Adding to the knowledge on patient and public involvement: reflections from an experience of co-research with carers of people with dementia. *Health Expectations*, *23*(3), 691-706.

Dix, L., Steggles. E., Baptiste, S., & Risdon, C. A process orientated approach to enhancing interprofessional education and collaborative relationship-centered care: the PIER project. *Journal of Interprofessional Care*. 2008(22), 321-324.

Doane, G. A. H. (2002). Beyond behavioral skills to humaninvolved processes: Relational nursing practice and interpretive pedagogy. *Journal of Nursing Education*, *41*(9), 400-404.

Dodds, P. (2003). Involving the recipients of dementia care in training for staff. *mental health practice*, *6*(10), 34-37.

Dombestein, H., Norheim, A., & Lunde Husebø, A. M. (2020). Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. *Scandinavian Journal of Caring Sciences*, *34*(2), 267-279.

Dowling M. 2006. Approaches to reflexivity in qualitative research. *Nurse Researcher*, *13*(3), 7–21.

Dwamena, F., Holmes-Rovner, M., Gaulden, C. M., Jorgenson, S., Sadigh, G., Sikorskii, A., Lewin, S., Smith, R. C., Coffey, J., & Olomu, A. (2012). Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews,* 12(CD003267), https://doi.org/10.1002/14651858.CD003267.pub2

Edvardsson, D., Winblad, B., & Sandman, P.-O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, *7*(4), 362-367.

Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010). Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, 19(17-18), 2611-2618.

Edvardsson, D., Sandman, P. O., & Borell, L. (2014). Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience. *International Psychogeriatrics*, *26*(7), 1171-1179.

Edvardsson, D., SJogren, K., Lood, Q., Bergland, A., Kirkevold, M., & Sandman, P. - O. (2017). A person-centred and thriving-promoting intervention in nursing homes - study protocol for the U-Age nursing home multi-centre, non-equivalent controlled group before-after trial. *BMC Geriatrics*, 17(22), 1-9.

Egan, T.M., & Lancaster, C.M. (2005). Comparing appreciative inquiry to action research: OD practitioner perspectives. *Organization Development Journal*, 23(2), 29-49.

El Hussein, M., Hirst, S., & Salyers, V. (2015). Factors that contribute to underrecognition of delirium by registered nurses in acute care settings: a scoping review of the literature to explain this phenomenon. *Journal of Clinical Nursing*, *24*(7-8), 906-915.

Ensher, G. L., & Clark, D. A*. (2011). Relationship-Centered Practices in Early Childhood: Working with Families, Infants, and Young Children at Risk*. Brookes.

Ervin, K., & Moore, S. (2014). Rural nurses' perceptions of a volunteer program in an acute setting: Volunteers delivering person-centred care for patients with dementia and delirium. *Open Journal of Nursing*, 4(1), 27-33.

Evans, M., Bergum, V., Bamforth, S., & MacPhail, S. (2004). Relational ethics and genetic counseling. *Nursing Ethics*, *11*(5), 459-471.

Fahie, D. (2014). Doing sensitive research sensitively: Ethical and methodological issues in researching workplace bullying. *International Journal of Qualitative Methods*, *13*(1), 19-36.

Fawcett, J. (2011). Family-centred care: what works and what does not work. *Journal of Advanced Nursing, 67*(5), 925-925.

Feast, A. R., White, N., Candy, B., Kupeli, N., & Sampson, E. L. (2020). The effectiveness of interventions to improve the care and management of people with dementia in general hospitals: A systematic review. *International Journal of Geriatric Psychiatry*, *35*(5), 463-488.

Feil, N. (1991). Validation therapy. *Serving the elderly*, 89-116.

Fick, D. M., Agostini, J. V., & Inouye, S. K. (2002). Delirium superimposed on dementia: a systematic review. *Journal of the American Geriatrics Society*, *50*(10), 1723-1732.

Fick, D., Steis, M. R., Mion, L. C., & Walls, J. L. (2011). Computerised delirium support for delirium superimposed on dementia in older adults. A pilot study. *Journal of Gerontology Nursing. 37*(4)*,* 39–47*.* https://doi.org/10.3928/00989134-20100930-01

Finefter-Rosenbluh I. (2017). Incorporating perspective taking in reflexivity. *International Journal of Qualitative Methods. 16*(1), 160940691770353.

Finlay L. (2002a). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, *2*(2), 209–230.

Finlay L. (2002b). “Outing” the researcher: the provenance, process, and practice of reflexivity. *Qualitative Health Research*, *12*(4), 531–545.

Firth-Cozens, J., & Cornwell, J. (2009). *Enabling compassionate care in acute hospital settings*. The King’s Fund.

Fitzpatrick, R., & Boulton, M. (1994). Qualitative methods for assessing health care. *Quality in Health Care*, *3*(2), 107-113.

Fitzpatrick, J. J. (1997). Building community: developing skills for interprofessional health professions education and relationship-centered care. *Families, Systems and Health, 15*, 393–400.

Flavin, T., & Sinclair, C. (2019). Reflections on involving people living with dementia in research in the Australian context. *Australasian Journal on Ageing*, *38*(2). 6-8.

Flicker, L., & Holdsworth, K. (2014). *Aboriginal and Torres Strait islander people and dementia: a review of the research*: Alzheimer's Australia.

Flick, U. (2019). The concepts of qualitative data: Challenges in neoliberal times for qualitative inquiry. *Qualitative Inquiry*, *25*(8), 713-720.
Foucault, M. (1980 [1977]). Power/knowledge: Selected interviews and other writings. New York: Pantheon

Fong, T. G., Tulebaev, S. R., & Inouye, S. K. (2009). Delirium in elderly adults: diagnosis, prevention and treatment. *Nature Reviews Neurology, 5*(4), 210-220.

Fong, T. G., Davis, D., Growdon, M. E., Albuquerque, A., & Inouye, S. K. (2015). The interface between delirium and dementia in elderly adults. *The Lancet Neurology*, *14*(8), 823-832.

Fong, T. G., Racine, A. M., Fick, D. M., Tabloski, P., Gou, Y., Schmitt, E. M., Hshieh, T. T., Metzger, E., Bertrand, S. E., Marcantonio, E. R., Jones, R. N., & Inouye, S. K. (2019). The caregiver burden of delirium in older adults with Alzheimer disease and related disorders. *Journal of the American Geriatrics Society*, *67*(12), 2587-2592.

Fong, T.G., & Inouye, S.K. (2022). The inter-relationship between delirium and dementia: the importance of delirium prevention. *Nature Reviews Neurology, 18*(10), 579–596. https://doi.org/10.1038/s41582-022-00698-7

Freshwater, D., & Stickley, T. (2004). The heart of the art: emotional intelligence in nurse education. *Nursing inquiry*, *11*(2), 91-98.

Frost, S. (2016). *Biocultural creatures: Toward a new theory of the human*. Duke University Press.

Fudge, N., Wolfe, C. D., & McKevitt, C. (2008). Assessing the promise of user involvement in health service development: ethnographic study. *Bmj*, *336*(7639), 313-317.

Gaboury, I., Lapierre, L. M., Boon, H., & Moher, D. (2011). Interprofessional collaboration within integrative healthcare clinics through the lens of the relationship-centered care model. *Journal of Interprofessional Care*, *25*(2), 124–30.

Galvin, J. E., Roe, C. M., Xiong, C., & Morris, J. C.(2006). Validity and reliability of the AD8 informant interview in dementia. *Neurology,* 67(11), 1942–1948.

Gentles, S. J., Jack, S. M., Nicholas, D. B.,& McKibbon, K. A. (2014). Critical approach to reflexivity in grounded theory. *The Qualitative Report*, *19*(44), 1-14.

Gergen, K. J. (1994). Realities and relationships: Soundings in social construction. Cambridge, MA: HarvardUniversity Press.

Gerrish, K., & Lacey, A. (2010). *The research process in nursing*. John Wiley & Sons.

Gerritsen, D. L., Oyebode, J., & Gove, D. (2018). Ethical implications of the perception and portrayal of dementia. *Dementia*, *17*(5), 596-608.

Giang, T. A., Koh, J. E. J., Cheng, L. J., Tang, Q. C., Chua, M. J., Liew, T. M., Wee, S. L., & Yap, P. L. K. (2023). Effects of Humanitude care on people with dementia and caregivers: A scoping review. *Journal of Clinical Nursing*, *32*(13-14), 2969-2984.

Gidman, J. (2013). Listening to stories: valuing knowledge from patient experience. *Nurse Education in Practice, 13*(3), 192-6.

Glasgow, R. E., Phillips, S. M., & Sanchez, M. A. (2014). Implementation science approaches for integrating eHealth research into practice and policy. *International Journal of Medical Informatics*, *83*(7), e1-e11.

Goeman, D. P., Corlis, M., Swaffer, K., Jenner, V., Thompson, J. F., Renehan, E., & Koch, S. (2019). Partnering with people with dementia and their care partners, aged care service experts, policymakers and academics: A co-design process. *Australasian journal on ageing*, *38*, 53-58.

Goldberg, S. E., Whittamore, K. H., Harwood, R. H., Bradshaw, L. E., Gladman, J. R. F., Jones, R. G., & Med Crises Older People Study, G. (2012). The prevalence of mental health problems among older adults admitted as an emergency to a general hospital. *Age and Ageing, 41*(1), 80-86.

Goldberg, S. E., Bradshaw, L. E., Kearney, F. C., Russell, C., Whittamore, K. H., Foster, P. E., Mamza, J., Gladman, J. R. F., Jones, R. G., Lewis, S. A., Porock, D., Harwood, R. H. (2013). Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial). *BMJ, 347*(f4132).

Goleman, D.(1995) *Emotional Intelligence.*Maryland: Bantam Books.

Goodrich, J., & Cornwell, J. (2008). Seeing the person in the patient. *The Point of Care review paper*. https://assets.kingsfund.org.uk/f/256914/x/f8d42c9e2e/seeing_the_person_in_patient_december_2008.pdf

Goossen, C., & Austin, M. J. (2017). Service user involvement in UK social service agencies and social work education. *Journal of Social Work Education*, *53*(1), 37-51.

Gordon, E. H., Ward, D. D., Xiong, H., Berkovsky, S., & Hubbard, R. E. (2024). Delirium and incident dementia in hospital patients in New South Wales, Australia: retrospective cohort study. *BMJ*, *384*(e077634).

Gove, D., Downs, M., Vernooij-Dassen, M. J. F. J., & Small, N. (2016). Stigma and GPs' perceptions of dementia. *Aging & Mental Health*, *20*(4), 391-400.

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R., ... & European Working Group of People with Dementia. (2018). Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & mental health*, *22*(6), 723-729.

Griffiths, A. W., Robinson, O. C., Shoesmith, E., Kelley, R., & Surr, C. A. (2021). Staff experiences of implementing Dementia Care Mapping to improve the quality of dementia care in care homes: a qualitative process evaluation. *BMC Health Services Research*, *21(138)*, 1-12.

Grossi, E., Lucchi, E., Gentile, S., Trabucchi, M., Bellelli, G., & Morandi, A. (2020). Preliminary investigation of predictors of distress in informal caregivers of patients with delirium superimposed on dementia. *Aging, Clinical and Experimental Research, 32*(2), 339-344.

Grosvenor, W., Gallagher, A., & Banerjee, S. (2021). Reframing dementia: Nursing students' relational learning with rather than about people with dementia. A constructivist grounded theory study. *International Journal of Geriatric Psychiatry*, *36*(4), 558-565.

Guba, E. G. (1989). *Fourth generation evaluation* (Vol. 294). Sage.

Guzmán, A., Wenborn, J., Ledgerd, R., & Orrell, M. (2017). Evaluation of a Staff Training Programme using Positive Psychology coaching with film and theatre elements in care homes: views and attitudes of residents, staff and relatives. *International Journal of Older People Nursing*, *12*(1), e12126. https//doi.org/10.1111/opn.12126

Gwernan-Jones, R., Lourida, I., Abbott, R. A., Rogers, M., Green, C., Ball, S., ... & Thompson Coon, J. (2020b). Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews. *Healh Services and Delivery Research,* 8 (43), 1-248

Haken, H. (1987). Synergetics. In F. E. Yates, A. Garfinkel, D. Walter, G. Yates (Ed.s). *Self-Organizing Systems: The Emergence of Order*. Plenum Press.

Hall, S., Longhurst, S., & Higginson, I. J. (2009). Challenges to conducting research with older people living in nursing homes. *BMC Geriatrics*, *9*(38).

Halloway, S. (2014). A family approach to delirium: a review of the literature. *Aging & Mental Health, 18*(2), 129-139.

Handforth, R. (2022). Feeling “stupid”: Considering the affective in women doctoral students’ experiences of imposter ‘syndrome’. In *The Palgrave handbook of imposter syndrome in higher education* (pp. 293-309). Springer International Publishing.

Handley, M., Bunn, F., & Goodman, C. (2017). Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review. *BMJ open*, *7*(7), e015257.

Handley, M., Bunn, F., & Goodman, C. (2019). Supporting general hospital staff to provide dementia sensitive care: A realist evaluation. *International Journal of Nursing Studies*, *96*, 61-71.

Handley, M., Bunn, F., Lynch, J., & Goodman, C. (2020). Using non-participant observation to uncover mechanisms: insights from a realist evaluation. *Evaluation*, *26*(3), 380-393.

Han, Q. Y. C., Rodrigues, N. G., Klainin-Yobas, P., Haugan, G., & Wu, X. V. (2022). Prevalence, risk factors, and impact of delirium on hospitalized older adults with dementia: a systematic review and meta-analysis. *Journal of the American Medical Directors Association*, *23*(1), 23-32.

Harrison Dening, K., & Aldridge, Z. (2021). Understanding behaviours in dementia. *Journal of Community Nursing*, *35*(3), 50-55.

Hasemann, W., Tolson, D., Godwin, J., Spirig, R., Frei, I. A., & Kressig, R. W. (2016). A before and after study of a nurse led comprehensive delirium management programme (DemDel) for older acute care inpatients with cognitive impairment. *International Journal of Nursing Studies*, *53*, 27-38.

Hatamleh, W. A., & Sorio, E. H. (2017). Knowledge, attitude and intention towards nursing profession among pre-clinical students. *Journal of Health Specialties*, *5*(3), 135.

Havens, D. S., Wood, S. O., & Leeman, J. (2006). Improving nursing practice and patient care: Building capacity with appreciative inquiry. *JONA: The Journal of Nursing, 36(10), 463-470.*

Helms, J., Kremer, S., Merdji, H., Clere-Jehl, R., Schenck, M., Kummerlen, C., Collange, O., Boulay, C., Fafi-Kremer, S., Ohana, M., Anheim, M., & Meziani, F. (2020). Neurologic features in severe SARS-CoV-2 infection. *New England Journal of Medicine*, *382*(23), 2268-2270.

Henriques LVL, Dourado MARF, Melo RCCP, Tanaka LH. Implementation of the Humanitude Care Methodology: contribution to the quality of health care. Rev Lat Am Enfermagem. 2019 Jan 17;27:e3123. doi: 10.1590/1518-8345.2430-3123. PMID: 30698221; PMCID: PMC6336364.

Higgins, J. P. & Green, S. 2008. Cochrane handbook for systematic reviews of interventions, Wiley Online Library

Hippocrates. (n.d.). Aphorismi. Retrieved from [source or publisher]

Hochschild, A. (1983). *The Managed Heart*. University of California.

Hodge, J., Foley, S., Brankaert, R., Kenning, G., Lazar, A., Boger, J., & Morrissey, K. (2020). Relational, flexible, everyday: learning from ethics in dementia research. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (pp. 1-16). Association for Computing Machinery.

Hoe, J., Hancock, G., Livingston, G., Woods, B., Challis, D., & Orrell, M. (2009). Changes in the quality of life of people with dementia living in care homes. *Alzheimer Disease and Associated Disorders*, *23*(3), 285-290.

Holt Clemmensen, T., Hein Lauridsen, H., Andersen-Ranberg, K., & Kaae Kristensen, H. (2021). Informal carers' support needs when caring for a person with dementia–A scoping literature review. *Scandinavian Journal of Caring Sciences*, *35*(3), 685-700.

Holloway, I., Brown, L., & Shipway, R. (2010). Meaning not measurement: Using ethnography to bring a deeper understanding to the participant experience of festivals and events. *International Journal of Event and Festival Management*, *1*(1), 74-85.

Holloway, I., & Galvin, K. (2023). *Qualitative research in nursing and healthcare*. John Wiley & Sons.*Administration*, *36*(10), 463-470.

Horgan, A., Manning, F., Donovan, M. O., Doody, R., Savage, E., Bradley, S. K., ... & Happell, B. (2020). Expert by experience involvement in mental health nursing education: the co-production of standards between experts by experience and academics in mental health nursing. *Journal of Psychiatric and Mental Health Nursing*, *27*(5), 553-562.

Hornstrup, C., & Johansen, T. (2009). From appreciative inquiry to inquiring appreciatively. *AI Practitioner*, *11*(3), 7-15.

Hosking, D. M., & Morley, I. (2004). Social constructionism in community and applied social psychology. Journal of Community and Applied Social Psychology, 14, 1–14.

Hosking, D. M. (2011). Telling Tales of Relations: Appreciating Relational Constructionism. Organization Studies, 32(1), 47-65. https://doi.org/10.1177/0170840610394296 (Original work published 2011)

Hshieh, T. T., Inouye, S. K., & Oh, E. S. (2018). Delirium in the elderly. *Psychiatric Clinics*, *41*(1), 1-17.

Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: challenges and strategies. *Aging & Mental Health*, *7*(5), 351-362.

Hughes, J. C. (2014). *How we think about dementia: personhood, rights, ethics, the arts and what they mean for care*. Jessica Kingsley Publishers.

Iaboni, A., Cockburn, A., Marcil, M., Rodrigues, K., Marshall, C., Garcia, M. A., Quirt, H., Reynolds, K. B., Keren, R., & Flint, A. J. (2020). Achieving safe, effective, and compassionate quarantine or isolation of older adults with dementia in nursing homes. *The American Journal of Geriatric Psychiatry, 28*(8), 835-838.

Iliffe, S., & Wilcock, J. (2005). The identification of barriers to the recognition of, and response to, dementia in primary care using a modified focus group approach. *Dementia*, *4*(1), 73-85.

Innes, A., Smith, S. K., & Bushell, S. (2021). Dementia friendly care: Methods to improve stakeholder engagement and decision making. *Journal of Healthcare Leadership*, 183-197. https://doi.org/10.2147/JHL.S292939

Inouye, S. K. (1999). Predisposing and precipitating factors for delirium in hospitalized older patients. *Dementia and geriatric cognitive disorders*, *10*(5), 393-400.

Inouye, S. K. (2000). Prevention of delirium in hospitalized older patients: risk factors and targeted intervention strategies. *Annals of Medicine*, *32*(4), 257-263.

Inouye, S. K., Westendorp, R. G., & Saczynski, J. S. (2014). Delirium in elderly people. *The Lancet*, *383*(9920), 911-922.

Instenes, I., Eide, L. S., Andersen, H., Fålun, N., Pettersen, T., Ranhoff, A. H., Rudolph, J. L., Martin Steihaug, O., Wentzel-Larsen, T., & Norekvål, T. M. (2024). Detection of delirium in older patients—A point prevalence study in surgical and non-surgical hospital wards. *Scandinavian Journal of Caring Sciences*, 38, 579-588.

James, I. A., & Stephenson, M. (2001). "The Newcastle Model: A Biopsychosocial Approach to Managing Challenging Behaviors in Dementia"**.** *Journal of Dementia Care*, 9(4), 22-27.

James, I. A., & Jackman, L. (2017). *Understanding behaviour in dementia that challenges: A guide to assessment and treatment*. Jessica Kingsley Publishers.

James, J., Fitzhenry, R., & Thompson, R. (2024). *Resolving Distress in Dementia: A Person-Centred Approach for Clinical Settings*. Jessica Kingsley Publishers.

Jayes, M., Austin, L., & Brown, L. J. (2022). Supported decision-making and mental capacity assessment in care homes: A qualitative study. *Health & Social Care in the Community*, *30*(4), e1061-e1069.

Johnson, R. B. (1997). Examining the validity structure of qualitative research. *Education*, 118(2), 282.

Johnson, B. H. (2000). Family-centered care: Four decades of progress. *Families, Systems, & Health, 18*(2), 137.

Jonsdottir, H., Litchfield, M., & Pharris, M. D. (2004). The relational core of nursing practice as partnership. *Journal of advanced nursing*, *47*(3), 241-248.

Julian, P., Ploeg,J., Kaasalainen S., & Markle-Reid, M. (2022). Building collaborative relationships with family caregivers of hospitalized older persons with delirium superimposed on dementia: A qualitative study. *Journal of Advanced Nursing, 79*(8), 2860-2870.

Kang, Y., Moyle, W., Cooke, M., & O'Dwyer, S. T. (2017). An educational programme to improve acute care nurses' knowledge, attitudes and family caregiver involvement in care of people with cognitive impairment. *Scandinavian Journal of Caring Sciences, 31*(3), 631-640. https://doi.org/10.1111/scs.12377

Karrer, M., Hirt, J., Zeller, A., & Saxer, S. (2020). What hinders and facilitates the implementation of nurse-led interventions in dementia care? A scoping review. *BMC geriatrics*, *20*, 1-13.

Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health affairs*, *34*(10), 1642-1649.

Kavanagh, T., Stevens, B., Seers, K., Sidani, S., & Watt-Watson, J. (2010). Process evaluation of appreciative inquiry to translate pain management evidence into pediatric nursing practice. *Implementation Science*, *5*, 1-13.

Kelley, R., Godfrey, M., & Young, J. (2019). The impacts of family involvement on general hospital care experiences for people living with dementia: an ethnographic study. *International journal of nursing studies*, *96*, 72-81.

Kennedy, M., Helfand, B. K., Gou, R. Y., Gartaganis, S. L., Webb, M., Moccia, J. M., Bruursema, S. N., Dokic, B., McCulloch, B., Ring, H., Margolin, J. D., Zhang, E., Anderson, R., Babine, T. G., Hshieh, T., Wong, A. H., Taylor, A., Davenport, K., Teresi, B. … & Inouye, S. K. (2020). Delirium in older patients with COVID-19 presenting to the emergency department. *JAMA network open*, *3*(11), e2029540-e2029540.

Kilbride, C., (2007). Inside the black box: creating excellence in stroke care through a community of practice. [PhD Thesis, City University, London]. City University, London. https://openaccess.city.ac.uk/id/eprint/17605/

Killick, J. (2013). *Dementia positive*. Luath Press Ltd.

Kim, B., Noh, G. O., & Kim, K. (2021). Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: a path analysis. *BMC geriatrics*, *21*, 1-12.

Kitwood, T., & Bredin, K. 1(1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society*, *12*, 269-287.

Kitwood T (1997) *Dementia Reconsidered, The Person Comes First.* Buckingham. Open University Press

Kitwood, T., & Bredin, K. (1997). Evaluating dementia care the DCM method. Bradford, England: Bradford Dementia Research Group, Bradford University.

Kitwood, T. (1997). Dementia reconsidered: the person comes first. In J. Katz, S. Peace & S. Spurr (eds.), *Adult lives* (pp. 89-99). Open University Press.

Kitwood,T. (1997a). *The concept of personhood and its relevance for a new cultrue of dementia care.* Routledge.

Kleinman A. (1988). *The Illness Narratives: Suffering, Healing and the Human Condition*. Basic Books. .

Knight, D. K., Wallace, G. L., Joe, G.W., & Logan, S. M. (2001). Change in psychosocial functioning and social relations among women in residential substance abuse treatment. *Journal of Substance Abuse, 13*(4), 533–47.

Krishnan, M. S., Jenkinson, J., & Negi, R. (2024). Liaison old age psychiatry management of delirium in acute Hospitals. In G. Tadros & G. Crowther (eds.) *Handbook of Old Age Liaison Psychiatry* (pp. 140-156). Cambridge University Press.

Kuehner, A., Ploder, A., & Langer, P. C. (2016). Introduction to the special issue: European contributions to strong reflexivity. *Qualitative Inquiry, 22*(9), 699–704.

Kvale, S. (2009). *Interviews: Learning the craft of qualitative research interviewing*. Sage.
Latour, B. (1987). Science in action. Milton Keynes: Open University Press.

Langford, J., & Clance, P. R. (1993). The imposter phenomenon: Recent research findings regarding dynamics, personality and family patterns and their implications for treatment. *Psychotherapy: theory, research, practice, training*, *30*(3), 495.

Lawton, J. (2001). Gaining and maintaining consent: ethical concerns raised in a study of dying patients. *Qualitative Health Research, 11*(5), 693-705.

Lee, S., Ro, G. S., Weber, M. T., & Oldham, M. A. (2025). The neuropsychiatric disturbances of delirium: A review of syndromes and their treatment. *The American Journal of Geriatric Psychiatry*.

Lee-Steere, K., Mudge, A., Liddle, J., & Bennett, S. (2024). Understanding family carer experiences and perceptions of engagement in delirium prevention and care for adults in hospital: Qualitative systematic review. *Journal of Clinical Nursing*, *33*(4), 1320-1345.

Leggatt-Cook, C., Sheridan, J., Madden, H., Cain, T., Munro, R., Tse, S. C., & Chamberlain, K. (2011). Collective reflexivity: Researchers in play: A play in one act. *Qualitative research in psychology*, *8*(3), 223-246.

Leighton, S. P., Herron, J. W., Jackson, E., Sheridan, M., Deligianni, F., & Cavanagh, J. (2022). Delirium and the risk of developing dementia: a cohort study of 12 949 patients. *Journal of Neurology, Neurosurgery & Psychiatry*, *93*(8), 822-827.

Leininger, M.M., (1985). *Qualitative research methods in nursing*. Grune and Stratton.

Levac, D., Colquhoun, H., & O'brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, *5*, 1-9.

Levesque, J.F., Harris, M.F., & Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health, 12*(1), 18. https://doi.org/10.1186/1475-9276-12-18

Liamputtong, P. (2006). *Researching the vulnerable: A guide to sensitive research methods*. Sage.

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P., Clarke, M., Devereaux, P. J., Kleijnen, J., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *Journal of clinical epidemiology, 62*(10), e1-e34.

Lim, X. M., Lim, Z. H. T., & Ignacio, J. (2022). Nurses' experiences in the management of delirium among older persons in acute care ward settings: A qualitative systematic review and meta-aggregation. *International Journal of Nursing Studies*, *127*, 104157.

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2024). Impact of dementia on informal care: a systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care*, *14*(e1), e38-e49.

Lipowski, Z. J. (1991). Delirium: how its concept has developed. *International Psychogeriatrics*, *3*(2), 115-120.

Littlechild R, Tanner D, & Hall K. (2015). Co-research with older people: perspectives on impact. *Qualitative Social Work, 14*(1):18–35. https://doi.org/10.1177/1473325014556791.

Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *JBI Evidence Implementation*, *13*(3), 179-187.

Lofland, J., & Lofland, L. H., (1984). *Analysing social settings* (2nd ed.). Wadsworth.

Logsdon, R. G., Gibbons, L. E., Mccurry, S. M., & TERI, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging*, 5, 21-32.

Lown, B. A., & Manning, C. F. (2010). The Schwartz Center Rounds: evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support. *Academic Medicine*, *85*(6), 1073-1081.

Ludema, J. D., & Fry, R. E. (2008). The practice of appreciative inquiry. *The SAGE handbook of action research: Participative inquiry and practice*, 280-296.

Luff, P., & Heath, C. (2015). Transcribing embodied action. *The handbook of discourse analysis*, 367-390.

Lwi, S. J., Ford, B. Q., Casey, J. J., Miller, B. L., & Levenson, R. W. (2017). Poor caregiver mental health predicts mortality of patients with neurodegenerative disease. *Proceedings of the National Academy of Sciences*, *114*(28), 7319-7324.

Maben, J., Peccei, R., Adams, M., Robert, G., Richardson, A., Murrells, T., & Morrow, E. (2012). Exploring the relationship between patients' experiences of care and the influence of staff motivation, affect and wellbeing. Final report.

NIHR service delivery and organization programme. https://www.kcl.ac.uk/nmpc/assets/nnru/nnru-report-exploring-the-relationship-between-patients-experiences-of-care-and-the-influence-of-staff-motivation-affect-and-wellbeing.pdf

Macbride, T., Dewar, B., & McNay, L. (2014, September 24-26). *Using Caring Conversations to adopt an appreciative stance to practice development*. [Conference paper]. Enhancing Practice 2014: Linking and transforming through practice development conference, Toronto, Canada.

MacBride, T., Miller, E., & Dewar, B. (2020). “I Know Who I Am; the Real Me, and That Will Come Back” The Importance of Relational Practice in Improving Outcomes for Carers of People With Dementia. *Illness, Crisis & Loss*, *28*(2), 119-140.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies, *British Journal of Psychology, 91*(1), 1–20.

Madigan, M. M. (2001). Relationship-centered care: what do the Fetzer Institute and physician well-being have to do with it? *Michigan Medicine*, *100*(3), 36–38.

Mailhot, T., Darling, C., Ela, J., Malyuta, Y., Inouye, S. K., & Saczynski, J. (2020). Family identification of delirium in the Emergency Department in patients with and without dementia: validity of the family confusion assessment method (FAM-CAM). *Journal of the American Geriatric Society, 68*(5), 983-990. https://doi.org/10.1111/jgs.16438

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet*, 358(9280), 483–488.

Marcantonio, E. R. (2017). Delirium in hospitalized older adults. *New England Journal of Medicine*, *377*(15), 1456-1466.

Martin, G. W., & Younger, D. (2000). Anti-oppressive practice: a route to the empowerment of people with dementia through communication and choice. *Journal of Psychiatric and Mental Health Nursing, 7*(1), 59-67.

Marrow, R. K., Cronin, C., Ashby, V., Currid, T., & Alexander, M. (2024). A Patient and Public Engagement Project to Inform Dementia Care in a UK Hospital Trust. *Health Expectations*, *27*(5), e70024.

Martinez, F. T., Tobar, C., Beddings, C. I., Vallejo, G., & Fuentes, P. (2012). Preventing delirium in an acute hospital using a non-pharmacological intervention. *Age and Ageing, 41*(5), 629-634.

Martinez, F., Tobar, C., & Hill, N. (2015). Preventing delirium: should non-pharmacological, multicomponent interventions be used? A systematic review and meta-analysis of the literature. *Age and ageing, 44*(2), 196-204. https://doi.org/10.1093/ageing/afu173

Maslow, A. (1970). *Motivation and Personality* (2 ed.). Harper & Row Publishers.

Mattison, M. L. (2020). Delirium. *Annals of internal medicine*, *173*(7), ITC49-ITC64.

McCance, T., Gribben, B., McCormack, B., & Laird, E.A. (2013) Promoting person-centred practice within acute care: the impact of culture and context on a facilitated practice development programme. *International Practice Development Journal, 3*(1), 1-14. https://www.fons.org/wp-content/uploads/2024/03/IDPJ_0301_02.pdf

McCormack, B. (2003). A conceptual framework for person-centred practice with older people. *International Journal of Nursing Practice, 9*(3), 202-209.

McCormack, B., & McCance, T. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing, 56*(5), 472-479.

McCormack, B., McCance, T., Slater, P., McCormick, J., McArdle, C., & Dewing, J. (2008). Person-centred outcomes and cultural change. In K. Manley, B. McCormack & V. Wilson (Eds.). (2008). *International Practice Development in Nursing and Healthcare (pp. 189-214)*. Blackwell.

McCormack, B. and McCance, T. (2010). *Person-centred Nursing: Theory and Practice*. Wiley Blackwell.

McCormack, B., Dewing, J. and McCance, T. (2011). Developing person-centred care: addressing contextual challenges through practice development. *Online Journal of Issues in Nursing*, 16(2), 1-12.

McCormack, B., Borg, M., Cardiff, S., Dewing, J., Jacobs, G., Janes, N., Karlsson, B., McCance, T., Mekki, T.E., Porock, D., Lieshout, F. V., & Wilson, V. (2015). Person-centredness – the 'state' of the art. *International Practice Development Journal, 5*(Supplement), 1.

McCormack, B., & McCance, T. (Eds.). (2016). *Person-centred practice in nursing and health care: theory and practice. John Wiley & Sons.*

McCusker, J., Cole, M., Abrahamowicz, M., Han, L., Podoba, J. E., & Ramman-Haddad, L. (2001). Environmental risk factors for delirium in hospitalized older people. *Journal of the American Geriatrics Society*, *49*(10), 1327-1334.

McKenzie, J., & Joy, A. (2020). Family intervention improves outcomes for patients with delirium: Systematic review and meta-analysis. *Australasian Journal on Ageing*, 39(1), 21–30. https://doi.org/10.1111/ajag.12688

McKillop, J., & Wilkinson, H. (2004). Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia*, *3*(2), 117-125.

McMillan, F., Kampers, D., Traynor, V., & Dewing, J. (2010) Person-centred caring as caring for country: An Indigenous Australian experience. *Dementia*, 9(2), 1-5.

Mendes, A., Herrmann, F. R., Périvier, S., Gold, G., Graf, C. E., & Zekry, D. (2021). Delirium in older patients with COVID-19: prevalence, risk factors, and clinical relevance. *The Journals of Gerontology: Series A*, *76*(8), e142-e146.

Merriel, A., Wilson, A., Decker, E., Hussein, J., Larkin, M., Barnard, K., O'Dair, M., Costello, A., Malata, A., & Coomarasamy, A. (2022). Systematic review and narrative synthesis of the impact of Appreciative Inquiry in healthcare. *BMJ Open Quality*, *11*(2), e001911.

Meyer, J. (2000). Using qualitative methods in health related action research. *Bmj*, *320*(7228), 178-181.

Miah, J., Dawes, P., Edwards, S., Leroi, I., Starling, B., & Parsons, S. (2019). Patient and public involvement in dementia research in the European Union: a scoping review. *BMC Geriatrics, 19*, 1-20.

Mitchell, G. (2023). *Delirium: Prevention, Diagnosis and Management in Hospital and Long-Term Care* (CG103). NICE. https://www.nice.org.uk/Guidance/CG103

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*, *151*(4), 264-269.

Moore, M. (2008). Appreciative inquiry: The why? The what? The how?. *Practice Development in Health Care*, *7*(4), 214-220.

Morandi, A., Davis, D., Fick, D. M., Turco, R., Boustani, M., Lucchi, E., Guerini, F., Morghen, S., Torpilliesi, T., Gentile, S., MacLullich, A. M., Trabucchi, M., & Bellelli, G. (2014). Delirium superimposed on dementia strongly predicts worse outcomes in older rehabilitation inpatients. *Journal of the American Medical Directors Association*, *15*(5), 349-354.

Morandi, A., Lucchi, E., Turco, R., Morghen, S., Guerini, F., Santi, R., Gentile, S., Meagher, D., Voyer, P., Fick, D. M., Schmitt, E. M., Inouye, S. K., Trabucchi, M., & Bellelli, G. (2015). Delirium superimposed on dementia: a quantitative and qualitative evaluation of informal caregivers and health care staff experience. *Journal of Psychosomatic Research*, *79*(4), 272-280.

Morandi, A., Davis, D., Bellelli, G., Arora, R. C., Caplan, G. A., Kamholz, B., Kolanowski, A., Fick, D. M., Kreisel, S., MacLullich, A., Meagher, D., Neufeld, K., Pandharipande, P. P., Richardson, S., Slooter, A. J. C., Taylor, J. P., Thomas, C., Tieges, Z., Teodorczuk, A., … & Rudolph, J. L. (2017). The diagnosis of delirium superimposed on dementia: an emerging challenge. *Journal of the American Medical Directors Association, 18*(1), 12-18.

Morandi, A., & Bellelli, G. (2020). Delirium superimposed on dementia. *European Geriatric Medicine*, *11*, 53-62.

Morandi, A., Grossi, E., Lucchi, E., Zambon, A., Faraci, B., Severgnini, J., MacLullich, A., Smith, H., Pandharipande, P., Rizzini, A., Galeazzi, M., Massariello, F., Corradi, S., Raccichini, A., Scrimieri, A., Marichi, V., Gentile, S., Lucchini, F., Pecorella, L. … & Bellelli, G. (2021). The 4-DSD: a new tool to assess delirium superimposed on moderate to severe dementia. *Journal of the American Medical Directors Association*, *22*(7), 1535-1542.

Morandi, A., Inzitari, M., Udina, C., Gual, N., Mota, M., Tassistro, E., ... & Tonon, E. (2021). Visual and hearing impairment are associated with delirium in hospitalized patients: results of a multisite prevalence study. *Journal of the American Medical Directors Association*, *22*(6), 1162-1167.

.

Morgan, N., Grinbergs-Saull, A., & Murray, M. (2018). ‘*We can make our research meaningful’. The impact of the Alzheimer’s Society Research* 2018. Retrieved June 18, 2018, from https://www.alzheimers.org.uk/sites/default/files/2018-04/Research%20Network%20Report%20low-res.pdf

Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R., & Gracia, N. (2011). Acute care management of older people with dementia: a qualitative perspective. *Journal of Clinical Nursing*, *20*(3-4), 420-428.

Mukadam, N., & Sampson, E. L. (2011). A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *International Psychogeriatrics, 23*(3), 344-355.

Mulhall, A. (2003). In the field: notes on observation in qualitative research. *Journal of Advanced Nursing, 41*, 306-313.

Munn, Z., Peters, M. D., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC medical research methodology*, *18*, 1-7.

Narayanasamy, A. (2015). Reflexive account of unintended outcomes from spiritual care qualitative research. *Journal of Research in Nursing*, *20*(3), 234-248.

National Institute from Health and Care Research NIHR. (2019) *PPI (patient and public involvement) resources for applicants to NIHR research programmes. Version 1.0 December 2019*. https://www.nihr.ac.uk/ppi-patient-and-public-involvement-resources-applicants-nihr-research-programmes

National Institute for Health and Care Excellance, NICE. (2023). Delirium: Prevention, diagnosis and management in hopsital and long term care. NICE. https://www.nice.org.uk/Guidance/CG103

Naveed, R. T., Alhaidan, H., Al Halbusi, H., & Al-Swidi, A. K. (2022). Do organizations really evolve? The critical link between organizational culture and organizational innovation toward organizational effectiveness: Pivotal role of organizational resistance. *Journal of Innovation & Knowledge*, *7*(2), 100178.

NHS England. (2015), *Introducing the 6CS*. Retrieved December 12, 2024, from https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/03/introducing-the-6cs.pdf?form=MG0AV3

National Health Service England. (2022). A plan for digital health and social care National Institute for Health and Clinical Excellance.

NICE, 2018. *Dementia: Assessment, management and support for people living with dementia and their carers.*NICE Guideline NG97 [online]. Available from:https://www.nice.org.uk/guideline/ng7.

Nicholson, C., & Barnes, J. (2013). Appreciative inquiry. *Participatory Research in Palliative Care: Actions and Reflections*, 64-73.

Nitchingham, A., & Caplan, G. A. (2021). Current challenges in the recognition and management of delirium superimposed on dementia. *Neuropsychiatric Disease and Treatment*, 1341-1352.

Nolan, M., Davies, S., & Grant, G. (2001). *Integrating perspectives* (pp. 160-178). Open University Press.

Nolan, M., Keady, J., & Aveyard, B. (2001). Relationship-centred is the next logical step. *British Journal of Nursing, 10*(12), 757.

Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of clinical nursing*, *13*, 45-53.

Nolan, M. R., Brown, J., Davies, S., Nolan, J., & Keady, J. (2006). *The Senses Framework: improving care for older people through a relationship-centred approach. Getting research into practice (GRiP) report no.2*. Sheffield Hallam University research archive. https://shura.shu.ac.uk/id/eprint/280

Nolan, M., Davis, S., & Brown, J. (2006). Transitions in care homes: towards relationship-centred care using the "Senses Framework." *Quality in Ageing and Older Adults*, *7*(3), 5–14.

Nolan, M., & Allan, S. (2012). The 'Senses Framework': A relationship-centred approach to care (pp.n100-109). In J. Katz, S. Peace & S. Spurr (eds.) *Adult Lives: A Life Course Perspective*. Policy Press.

Norman, R. (2006). Observations of the experiences of people with dementia on general hospital wards. *Journal of Research in Nursing*, *11*(5), 453-465.

Novak, L. L., George, S., Wallston, K. A., Joosten, Y. A., Israel, T. L., Simpson, C. L., Vaughn, Y., Williams, N. A., Stallings, S., Ichimura, J. S., & Wilkins, C. H. (2020). Patient Stories Can Make a Difference in Patient-Centered Research Design. *Journal of Patient Experience*, *7*(6), 1438-1444. https://doi.org/10.1177/2374373520958340

NSW Agency for Clinical Innovation. (2014). *Volunteer dementia & delirium care implementation and training resource*. Australian Commission on Safety and Quality in Health Care. https://cognitivecare.gov.au/information/volunteer-dementia-and-delirium-care-implementation-and-training-resource/

Novek, S., & Wilkinson, H. (2019). Safe and inclusive research practices for qualitative research involving people with dementia: A review of key issues and strategies. *Dementia*, *18*(3), 1042-1059.

Nydahl, P., Ely, E.W., & Heras-La Calle, G. Humanizing Delirium Care. *Intensive Care Medicine* **50**, 469–471 (2024). https://doi.org/10.1007/s00134-024-07329-3

Office for National Statistics, (2023), Deaths registered in England and Wales. Deaths registered in England and Wales - Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2023. Retrieved January 11, 2025.

O'Hanlon, S., O'Regan, N., Maclullich, A., Cullen, W., Dunne, C., Exton, C., & Meagher, D. (2014). Improving delirium care through early intervention: from bench to bedside to boardroom. *Journal of Neurology, Neurosurgery, and Psychiatry, 85*(2), 207-213.

Oh, E. S., Fong, T. G., Hshieh, T. T., & Inouye, S. K. (2017). Delirium in older persons: advances in diagnosis and treatment. *JAMA*, *318*(12), 1161-1174.

Oliveira, D., da Mata, F. A. F., & Aubeeluck, A. (2024). Quality of life of family carers of people living with dementia: review of systematic reviews of observational and intervention studies. *British Medical Bulletin*, *149*(1), 1-12.

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, *45*(3), 241-251.

Page, K. (2012). The four principles: Can they be measured and do they predict ethical decision making?. *BMC Medical Ethics*, *13*, 1-8.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hrobjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, *372,* n71.

Panel on Interdisciplinary/Transdisciplinary Education. (1997). Building community: developing skills for interprofessional health professions education and relationship-centered care. *Families, Systems and Health, 15*, 393–400.

Park, H. Y. (2024). Hospital space interpreted according to Heidegger's concepts of care and dwelling. *Medical Humanities*, *50*(1), 135-143.

Patterson, M., Nolan, M., Rick, J., Brown, J., & Adams, R. (2010). *From metrics to meaning: culture change and quality of acute hospital care for older people* (Report for the National Co-Ordinating Centre for NHS Service Delivery & Organisation (NCCSDO)). NHS Service Delivery and Organisation R & D (NCCSDO).

Paulson, C. M., Monroe, T., McDougall, J. G. J., & Fick, D. M. (2016). A Family-Focused Delirium Educational Initiative With Practice and Research Implications. *Gerontology & Geriatrics Education, 37*(1), 4-11.

Parke, B., Hunter, K. F., Schulz, M. E., & Jouanne, L. (2019). Know me – A new person-centered approach for dementia-friendly emergency department care. *Dementia*, *18*(2), 432-447.

Parveen, S., Smith, S. J., Sass, C., Oyebode, J. R., Capstick, A., Dennison, A., & Surr, C. A. (2021). Impact of dementia education and training on health and social care staff knowledge, attitudes and confidence: a cross-sectional study. *BMJ open*, *11*(1), e039939.

Penfold, R. S., Hall, A. J., Anand, A., Clement, N. D., Duckworth, A. D., & MacLullich, A. M. (2023). Delirium in hip fracture patients admitted from home during the COVID-19 pandemic is associated with higher mortality, longer total length of stay, need for post-acute inpatient rehabilitation, and readmission to acute services: the IMPACT Delirium study. *Bone & Joint Open*, *4*(6), 447-456.

Pennington, H., & Isles, C. (2013). Should hospitals provide all patients with single rooms? *BMJ*, *347*, f5695. https://doi.org/10.1136/bmj.f5695

Pepper, A., & Dening, K.H. (2023). Dementia and communication. *British Journal of Community Nursing*, 28(12), 592-597. https://doi.org/10.12968/bjcn.2023.28.12.592

Perrin, T. (1997). The positive response schedule for severe dementia. *Aging & Mental Health*, *1*(2), 184-191.

Peters, M. D., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI evidence synthesis*, *18*(10), 2119-2126.

Pilnick, A. (2023). Reconsidering patient-centred care: Authority, expertise and abandonment. *Health Expectations*, *26*(5), 1785-1788.

Pollard, C. (2015). What is the right thing to do: use of a relational ethic framework to guide clinical decision-making. *International Journal of Caring Sciences, 8*(2), 362-368. https://hdl.handle.net/20.500.14078/785

Poloni, T. E., Carlos, A. F., Cairati, M., Cutaia, C., Medici, V., Marelli, E., Ferrari, D., Galli, A., Bognetti, P., Davin, A., Cirrincione, A., Ceretti, A., Cereda, C., Ceroni, M., Tronconi, Vitali, S., & Guaita, A. (2020). Prevalence and prognostic value of Delirium as the initial presentation of COVID-19 in the elderly with dementia: An Italian retrospective study. *EClinicalMedicine*, *26, 100490*.

Poon, E. (2022). A systematic review and meta-analysis of dyadic psychological interventions for BPSD, quality of life and/or caregiver burden in dementia or MCI. *Clinical Gerontologist*, *45*(4), 777-797.

Pope, C. A. (1999). Reflection and refraction: A reflexive look at an evolving model for methods instruction. *English Education*, *31*(3), 177-200.

Pope, C., & Mays, N. (Eds.). (2013). Qualitative research in health care. Blackwell.

Porock, D., Clissett, P., Harwood, R. H., & Gladman, J. R. (2015). Disruption, control and coping: responses of and to the person with dementia in hospital. *Ageing & Society*, *35*(1), 37-63.

Pranata, R., Huang, I., Lim, M. A., Yonas, E., Vania, R., & Kuswardhani, R. A. T. (2021). Delirium and mortality in coronavirus disease 2019 (COVID-19)–a systematic review and meta-analysis. *Archives of Gerontology and Geriatrics*, *95*, 104388.

Quinn, T. J., Mooijaart, S. P., Gallacher, K., & Burton, J. K. (2019). Acute care assessment of older adults living with frailty. *BMJ*, *364*, l13.

Quinn, C., Nelis, S. M., Martyr, A., Victor, C., Morris, R. G., Clare, L., & IDEAL Study Team. (2019). Influence of positive and negative dimensions of dementia caregiving on caregiver well-being and satisfaction with life: findings from the IDEAL study. *The American Journal of Geriatric Psychiatry*, *27*(8), 838-848.

Reed, J. (2006). *Appreciative inquiry: Research for change*. Sage publications.

Reed, J., & Procter, S. (Eds.). (1995). *Practitioner research in health care*. Chapman & Hall

Reed, J., & McCormack, B. (2007). The importance of dignity. *International Journal of Older People Nursing*, *2*(3), 161-161.

Reed, J. (2007). *Appreciative inquiry: Research for change*. Sage.

Reed, J., Richardson, E., Marais, S., & Moyle, W. (2008). Older people maintaining well-being: an International Appreciative Inquiry study. *International Journal of Older People Nursing*, *3*(1), 68-75.

Reynish, E. L., Hapca, S. M., De Souza, N., Cvoro, V., Donnan, P. T., & Guthrie, B. (2017). Epidemiology and outcomes of people with dementia, delirium, and unspecified cognitive impairment in the general hospital: prospective cohort study of 10,014 admissions. *BMC medicine, 15*(1), 140.

Richardson, S. J., Davis, D. H., Stephan, B. C., Robinson, L., Brayne, C., Barnes, L. E., Taylor, J.-P., Parker, S. G., & Allan, L. M. (2021). Recurrent delirium over 12 months predicts dementia: results of the Delirium and Cognitive Impact in Dementia (DECIDE) study. *Age and Ageing*, *50*(3), 914-920.

Richer, M. C., Ritchie, J., & Marchionni, C. (2010). Appreciative inquiry in health care. *British Journal of Healthcare Management*, *16*(4), 164-172.

Ries, N. M., Mansfield, E., & Sanson-Fisher, R. (2020). Ethical and legal aspects of research involving older people with cognitive impairment: A survey of dementia researchers in Australia. *International Journal of Law and Psychiatry*, *68*, 101534.

Robinson, T. N., Raeburn, C. D., Tran, Z. V., Brenner, L. A., & Moss, M. (2011). Motor subtypes of postoperative delirium in older adults. *Archives of Surgery*, *146*(3), 295-300.

Rockwood, K., Cosway, S., Carver, D., Jarrett, P., Stadnyk, K. , & Fisk, J. (1999). The risk of dementia and death after delirium. *Age and Ageing*, *28*(6), 551-556.

Roden, M., & Simmons, B. B. (2014). Delirium superimposed on dementia and mild cognitive impairment. *Postgraduate Medicine, 126*(6), 129-137. doi:10.3810/pgm.2014.10.2827

Rogers, C (1961) *On Becoming a Person.*London. Robinson

Rooney, D. (2019). *A study of the importance of establishing a relationship between emotional intelligence and dementia care for the provision of person-centred care by home care workers in the non-for-profit sector* (Doctoral dissertation, Dublin, National College of Ireland).

Rose, N. (1998). *Inventing our selves: Psychology, power, and personhood*. Cambridge University Press.

Rosen, M. (2023, February 07). On living with long COVID-19 and other traumas. *Offlay Express*, https//www.offalyexpress.ie/news/lifestyle/1030109/author-michael-rosen-on-living-with-long-covid-and-other-traumas.html

Royal College of Psychiatrists. (2011). *Report of the National Audit of Dementia in Hospital, 2011.* Healthcare Quality Improvement Partnership. https://www.hqip.org.uk/wp-content/uploads/2018/02/report-of-the-national-audit-of-dementia-care-in-general-hospitals-2011.pdf

Royal College of Psychiatrists (RCP), 2019a. *National Audit of Dementia Care in General Hospitals 2018-2019: Round four audit report.* London:RCP [online]. Available from: https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/r4-resources/reports-core-audit/national-audit-of-dementia-round-4-report-online.pdf.

Royal College of Psychiatrists. (2024). *National Audit of Dementia, 2024.* https://www.rcpsych.ac.uk/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia

Ruff, M. W., Fine, A., Mandrekar, J., Sweeney, C., Jones Jr, L. K., & Klaas, J. P. (2018). Activity aprons for inpatients requiring individual nursing assignment care: A prospective randomized controlled pilot study. *The Neurohospitalist*, *8*(4), 183-187.

Russell GM, Kelly NH. 2002. Research as interacting dialogic processes: implications for reflexivity. *Forum Qualitative Sozialforschung / Qualitative Social Research, 3*(3), 831

Ryan, T., Nolan, M., Reid, D. and Enderby, P. (2008) Using the Senses Framework to achieve relationship centred dementia care services. *Dementia, 7*(1), 71-93.

Sabat, S. R., Downs, M., & Bowers, B. (2008). *Excellence in dementia care: Research into practice.* Open University Press.

Safran, D. G., Miller, W., & Beckman, H. (2006). Organizational dimensions of relationship-centered care. *Journal of General Internal Medince, 21*, 9–15.

Sampson, E. L., Stringer, A., La Frenais, F., Higgins, S., Doyle, M. J., Laybourne, A., Livingston, G., & Leavey, G. (2019). Agitation near the end of life with dementia: an ethnographic study of care. *PloS One*, *14*(10), e0224043.

Sandelowski, M., (1991). Telling stories: Narrative approaches in qualitative research. Image: *Journal of Nursing Scholarship, 23*(3), 161-166.

Sass, C., Burnley, N., Drury, M., Oyebode, J., & Surr, C. (2019). Factors associated with successful dementia education for practitioners in primary care: an in-depth case study. *BMC medical education*, *19*, 393 1-7.https//doi.org/10.1186/s12909-019-1833-2

Scales, K., Bailey, S., Middleton, J., & Schneider, J. (2017). Power, empowerment, and person-centred care: using ethnography to examine the everyday practice of unregistered dementia care staff. *Ageing, Dementia and the Social Mind*, 52-68.

Scammell, J., Heaslip, V., & Crowley, E. (2016). Service user involvement in preregistration general nurse education: a systematic review. *Journal of Clinical Nursing*, *25*(1-2), 53-69.

Scerri, A., Innes, A., Scerri, C., Stacpoole, M., Hockley, J., Thompsell, A., ... & Anstey, K. J. (2015). Physical and Psychological Distress Are Related to Dying Peacefully in Residents With. *Journal of Pain and Symptom Management*, *50*(1), 1-8.

Scerri, A., Innes, A., & Scerri, C. (2015). Discovering what works well: exploring quality dementia care in hospital wards using an appreciative inquiry approach. *Journal of Clinical Nursing*, *24*(13-14), 1916-1925.

Scerri, A., Innes, A., & Scerri, C. (2019). Using appreciative inquiry to implement person-centred dementia care in hospital wards. *Dementia*, *18*(1), 190-209.

Schmitt, E. M., Gallagher, J., Albuquerque, A., Tabloski, P., Lee, H. J., Gleason, L., & Inouye, S. K. (2017). Perspectives on the Delirium Experience and Its Burden: Common Themes Among Older Patients, Their Family Caregivers, and Nurses. *The Gerontologist* 59(2): 327-337.

Schneider, J. (2010). support workers play vital role in dementia care. *British Journal of Healthcare Assistants*, *4*(10), 498-501.

Scottish Intercollegiate Guidelines Network (SIGN). Guideline title. Edinburgh: SIGN; Year. (SIGN publication no. xxx). [cited 05 01 2025]. Available from URL: http://www.sign.ac.uK

SEALE, C. (1999). Quality in qualitative research. *Qualitative Inquiry, 5*, 465-478.

Sepúlveda, E., Bermúdez, E., Vallinoto, L., Sánchez, J., Saura, P., Piany, P., ... & Franco, J. G. (2025). Screening time for delirium in dementia patients matters: Validation of the Spanish version of the RADAR. *The European Journal of Psychiatry*, *39*(2), 100272.

Shakespeare, T., Zeilig, H., & Mittler, P. (2019). Rights in mind: Thinking differently about dementia and disability. *Dementia*, *18*(3), 1075-1088.

Sharp, C., Dewar, B., Barrie, K., & Meyer, J. (2018). How being appreciative creates change–theory in practice from health and social care in Scotland. *Action Research*, *16*(2), 223-243.

Sheard, D,M. (2007). *Being: An approach to life and dementia.* Dementia Care Matters.

Sheard, D,M (2022). *Valuing 'nous': injecting care with a booster of emotional intelligence.*The Journal of Dementia Care. March/April 2022. Vol 30 No 2.pg26

Sherry, E. (2013). The vulnerable researcher: Facing the challenges of sensitive research. *Qualitative Research Journal*, *13*(3), 278-288.

Shrestha, P., & Fick, D. M. (2020). Family caregiver's experience of caring for an older adult with delirium: A systematic review. *International Journal of Older People Nursing*, *15*(4), e12321.

SIGN 157. (2019). Risk Reduction and Management of Delrium: A national clinical guideline.Healthcare Improvement Scotland. https://www.sign.ac.uk/media/1423/sign157.pdf

Silva, O., Cascio, M. A., & Racine, E. (2020). Person-oriented research ethics and dementia: The lack of consensus. *Anthropology & Aging*, *41*(1), 31-51.

Silverman, D. (2013). *Doing qualitative research: A practical handbook*. SAGE.

Simard, J., & Volicer, L. (2010). Namaste care and dying in institutional settings. *Supportive Care for the Person with Dementia*. Oxford University Press*, pp.*291-300.

Slater, L. (2006). Person-centredness: A concept analysis. *Contemporary Nurse, 23*, 135-144.

Smith, S., Dewar, B., Pullin, S., & Tocher, R. (2010). Relationship centred outcomes focused on compassionate care for older people within in-patient care settings. *International Journal of Older People Nursing*, *5*(2), 128-136.

Smith, S. J., Parveen, S., Sass, C., Drury, M., Oyebode, J. R., & Surr, C. A. (2019). An audit of dementia education and training in UK health and social care: a comparison with national benchmark standards. *BMC health services research*, *19*, 711, 1-9.https://doi.org/10.1186/s12913-019-4510-6

Smith, A. F., & Plunkett, E. (2019). People, systems and safety: resilience and excellence in healthcare practice. *Anaesthesia*, *74*(4), 508-517.

Smith, L., Morton, D., & Van Rooyen, D. (2022). Family dynamics in dementia care: a phenomenological exploration of the experiences of family caregivers of relatives with dementia. *Journal of Psychiatric and Mental Health Nursing*, *29*(6), 861-872.

Soklaridis PhD, S., Adler Nevo MD FRCPC, G., & Leif PRCPC, L. M. (2016). Relationship-centred care in health: A 20-year scoping review. *Patient Experience Journal*, *3*(1), 130-145.

Soun, S., Hunter, K. F., & Dahlke, S. (2023). Nursing Care Management of Responsive Behaviors for Persons Living With Dementia in Acute Care Settings: An Interative Review. *Journal of Gerontological Nursing, 49*(2), 19-25.

Stanyon, M. R., Griffiths, A., Thomas, S. A., & Gordon, A. L. (2016). The facilitators of communication with people with dementia in a care setting: an interview study with healthcare workers. *Age and ageing*, *45*(1), 164-170.

Stavros, J. M., Stavros, J., & Torres, C. (2021). *Conversations worth having: Using appreciative inquiry to fuel productive and meaningful engagement*. Berrett-Koehler.

Stenvall, M., Berggren, M., Lundström, M., Gustafson, Y., & Olofsson, B. (2012). A multidisciplinary intervention program improved the outcome after hip fracture for people with dementia—subgroup analyses of a randomized controlled trial. *Archives of Gerontology and Geriatrics*, *54*(3), e284-e289

Stevenson, M., & Taylor, B. J. (2019). Involving individuals with dementia as co-researchers in analysis of findings from a qualitative study. *Dementia*, *18*(2), 701-712.

Stewart, H., Smith, S., Baxter, R., Ali-Knight, J., & Kerr, G. (2022). Unlock & revive: The ingredients needed to deliver accessible online cultural and heritage events that bring positive benefits to people living with dementia. Edinburgh Napier University. https://napier-repository.worktribe.com/output/2836059

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research techniques*. SAGE.

Strøm, B. S., Engedal, K., & Andreassen, L. (2019). Nursing Staff's Knowledge and Attitudes toward Dementia: A Pilot Study from an Indian Perspective. *Dementia and Geriatric Cognitive Disorders Extra*. 9(3), 352-361. https://doi.org/10.1159/000502770

Suárez-González, A., Rajagopalan, J., Livingston, G., & Alladi, S. (2021). The effect of COVID-19 isolation measures on the cognition and mental health of people living with dementia: A rapid systematic review of one year of quantitative evidence. *EClinicalMedicine*, *39*.

Suchman, A. L.(2006). A new theoretical foundation for relationship-centered care. *Journal of General Internal Medicine*, *21*(Supplement 1), 40–4.

Suchman, A. L., Sluyter, D.J., & Williamson, P. R. (2011). *Leading Change in Healthcare: Transforming Organizations Using Complexity, Positive Psychology and Relationship-Centered Care*. Radcliffe.

Surr, C. A., Gates, C., Irving, D., Oyebode, J., Smith, S. J., Parveen, S., ... & Dennison, A. (2017). Effective dementia education and training for the health and social care workforce: a systematic review of the literature. *Review of educational research*, *87*(5), 966-1002.

Surr, Claire A., Cara Sass, Natasha Burnley, Michelle Drury, Sarah J. Smith, Sahdia Parveen, Sarah Burden, and Jan Oyebode. "Components of impactful dementia training for general hospital staff: a collective case study." *Aging & Mental Health* 24, no. 3 (2020): 511-521.

Surr, C. A., Sass, C., Drury, M., Burnley, N., Dennison, A., Burden, S., & Oyebode, J. (2019b). A collective case study of the features of impactful dementia training for care home staff. *Bmc Geriatrics*, *19*, 175. https://doi.org/10.1186/s12877-019-1186-z

Surr, C., Latham, I., & Smith, S. J. (2023). *Education and Training in Dementia Care: A Person-centred Approach*. McGraw-Hill Education (UK).

Surr, C., Sass, C., Griffiths, A., Oyebode, J., Smith, S., Parveen, S., & Drury, M. (2017). Dementia training design and delivery audit tool (DeTDAT) v4. 0. *Leeds: Leeds Beckett University*.

Surr, C., Latham, I., & Smith, S. J. (2023). *Education and Training in Dementia Care: A Person-centred Approach*. McGraw-Hill Education (UK).

Tahira, A. C., Verjovski-Almeida, S., & Ferreira, S. T. (2021). Dementia is an age-independent risk factor for severity and death in COVID-19 inpatients. *Alzheimer's & Dementia*, *17*(11), 1818-1831.

Tanner, D. (2012). Co-research with older people with dementia: Experience and reflections. *Journal of Mental Health*, *21*(3), 296-306.

Teahan, Á., Lafferty, A., Cullinan, J., Fealy, G., & O'Shea, E. (2021). An analysis of carer burden among family carers of people with and without dementia in Ireland. *International Psychogeriatrics*, *33*(4), 347-358.

Teodorczuk, A., Mukaetova-Ladinska, E., Corbett, S., & Welfare, M. (2014). Learning about the patient: an innovative interprofessional dementia and delirium education programme. *The Clinical Teacher, 11*(7), 497-502. https://doi.org/10.1111/tct.12203

Teodorczuk, A., Mukaetova-Ladinska, E., Corbett, S., & Welfare, M. (2015). Deconstructing dementia and delirium hospital practice: using cultural historical activity theory to inform education approaches. *Advances in Health Sciences Education, 20*(3), 745-764.

Thomasma, D. C. (1996). The ethics of managed care: challenges to the principles of relationship-centered care. *Journal of Allied Health*, *25*(3), 233–246.

Timmons, S., Manning, E., Barrett, A., Brady, N. M., Browne, V., O'Shea, E., Molloy, D. W., O'Regan, N. A., Trawley, S., Cahill, S., O'Sullivan, K., Woods, N., Meagher, D., Ni Chorcorain, A., & Linehan, J. (2015). Dementia in older people admitted to hospital: a regional multi-hospital observational study of prevalence, associations and case recognition. *Age and ageing, 44*(6), 993-999.

Tomaselli, G., Buttigieg, S. C., Rosano, A., Cassar, M., & Grima, G. (2020). Person-centred care from a relational ethics perspective for the delivery of high quality and safe healthcare: a scoping review. *Frontiers in public health*, *8*, 489949.

Torjesen, I. (2020). Figures show big increase in emergency admissions for dementia patients. *BMJ*, *368,* m249.

Torjesen, I. (2022). COVID-19 patients discharged from hospital have “substantially higher risk” of adverse outcomes and need monitoring. *BMJ, 376*, o265.

Tortosa-Alted, R., Reverte-Villarroya, S., Martinez-Segura, E., Lopez-Pablo, C., & Berenguer-Poblet, M. (2021). Emergency handover of critical patients. A systematic review. *International emergency nursing*, *56*, 100997.

Trajkovski, S., Schmied, V., Vickers, M., & Jackson, D. (2013). Implementing the 4D cycle of appreciative inquiry in health care: a methodological review. *Journal of Advanced Nursing*, 69, 1224-1234.

Travers, C., Henderson, A., Graham, F., & Beattie, E. (2018). CogChamps: impact of a project to educate nurses about delirium and improve the quality of care for hospitalized patients with cognitive impairment. *BMC Health Services Research*, *18*, 1-13.

Tresolini, C. P., & Pew-Fetzer Task Force. (1994). Health Professions Education and Relationship-Centered Care. Pew Health Professions Commission. https://rccswmi.org/uploads/PewFetzerRCCreport.pdf

Tricco, A. C., E. Lillie, W. Zarin, O’Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D., Horsley, T., Weeks, L., & Hempl, S. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine, 169*(7), 467–473. https://doi.org/10.7326/M18-0850

Triliva, S., Ntani, S., Giovazolias, T., Kafetsios, K., Axelsson, M., Bockting, C., & Øverland, S. (2020). Healthcare professionals’ perspectives on mental health service provision: a pilot focus group study in six European countries. *International Journal of Mental Health Systems*, *14*, 16 1-18. https://doi.org/10.1186/s13033-02000350-1

Tufanaru, C., Munn, Z., Aromateris E, Campbell J, Hopp, L. (2020). Chapter 3: Systematic reviews of effectivness. In: E. Aromataris, Z. Munn (Editors). *JBI Manual for Evidence Synthesis*. JBI. https://jbi-global-wiki.refined.site/space/MANUAL

Tulebaev, S. R., Inouye, S. K., & Fong, T. G. (2009). Delirium in elderly adults: diagnosis, prevention and treatment. *Nature Reviews Neurology, 5*(4), 210-220. https://doi.org/10.1038/nrneurol.2009.24

Ulrich, R. S., Zimring, C., Zhu, X., DuBose, J., Seo, H. B., Choi, Y. S., Quan, X., & Joseph, A. (2008). A review of the research literature on evidence-based healthcare design. *HERD: Health Environments Research & Design Journal*, *1*(3), 61-125.

Van Corven, C. T., Bielderman, A., Lucassen, P. L., Verbeek, H., Lesman-Leegte, I., Depla, M. F., Stoop, A., Graff, M. J. L., & Gerritsen, D. L. (2022). Family caregivers' perspectives on their interaction and relationship with people living with dementia in a nursing home: a qualitative study. *BMC Geriatrics*, *22*(1), 212.

Van der Haar, D., & Hosking, D. M. (2004). Evaluating appreciative inquiry: A relational constructionist perspective. *Human Relations*, *57*(8), 1017-1036.

Von Dietze, E., & Orb, A. (2000). Compassionate care: a moral dimension of nursing. *Nursing Inquiry,* 7(3), 166-174.

Van Graas, R., & Gobbens, R. J. (2023, June). Learning and Developing Together for Improving the Quality of Care in a Nursing Home, Is Appreciative Inquiry the Key? *Healthcare,* 11(13), 1840.

Voyer, P., Champoux, N., Desrosiers, J., Landreville, P., McCusker, J., Monette, J., ..., & Carmichael, P. H. (2015). Recognizing acute delirium as part of your routine [RADAR]: a validation study. *BMC Nursing*, *14*, 1-13.

Walker, P. H., Baldwin, D., Fitzpatrick, J. J., Ryan, S., Bulger, R., DeBasio, N., (1997). Building community: developing skills for interprofessional health professions education and relationship-centered care. *Journal of the Amercian Academy of Nurse Practioners, 9*(9), 413–417

Walker, P.H., Baldwin, D., Fitzpatrick, J.J., Ryan, S., Bulger, R., DeBasio, N., Hanson, C., Harvan, R., Johnson-Pawlson, J., Lacey, B., Ladden, M. J. (1998). Building community: developing skills for interprofessional health professions education and relationship-centered care. *Journal of Gerontology Nursing.* 24(3), 45–49.

Walsh, P. G., Mertin, P. G., Verlander, D. F., & Pollard, C. F. (1995). The effects of a 'pets as therapy' dog on persons with dementia in a psychiatric ward. *Australian Occupational Therapy Journal*, *42*(4), 161-166.

Walsh, R. (2003). The methods of reflexivity. *Humanistic Psychologist, 31*(4), 51–66.

Wang, H., Li, T., Barbarino, P., Gauthier, S., Brodaty, H., & Molinuevo, J., & Weidner, W. (2020). Dementia care during COVID-19. *The Lancet, 395*(10231), 1190-1191.

Watkins, J. M., & Mohr, B. (2001). Appreciative inquiry: Change at the speed of imagination. *Organization Development Journal*, *19*(3), 92.

Wass, V., (2018). Educating the mind without educating the heart is no education at all. *Education for Primary Care,* 29(2), 63. https://www.tandfonline.com/doi/pdf/10.1080/14739879.2018.1439307

Waszynski, C. M., Milner, K. A., Staff, I., & Molony, S. L. (2018). Using simulated family presence to decrease agitation in older hospitalized delirious patients: A randomized controlled trial. *International journal of nursing studies, 77*, 154-161.

Watkins, J. M., Mohr, B. J., & Kelly, R. (2011). *Appreciative inquiry: Change at the speed of imagination*. John Wiley & Sons.

Watkins, S., Dewar, B., & Kennedy, C. (2016). Appreciative Inquiry as an intervention to change nursing practice in in-patient settings: An integrative review. *International Journal of Nursing Studies*, *60*, 179-190.

Watkins, S., Murphy, F., Kennedy, C., Dewar, B., & Graham, M. (2019). Caring for an older person with dementia in the Emergency Department (ED): An Appreciative Inquiry exploring family member and ED nurse experiences. *Journal of Clinical Nursing*, *28*(15-16), 2801-2812.

Webster, J., & Dewing, J. (2007). Growing a practice development strategy for community hospitals. *Practice Development in Health Care*, *6*(2), 97-106.

Whitney, D. D., & Trosten-Bloom, A. (2010). *The power of appreciative inquiry: A practical guide to positive change*. Berrett-Koehler Publishers.

Wilson, P., Mathie, E., Poland, F., Keenan, J., Howe, A., Munday, D., ... & Goodman, C. (2018). How embedded is public involvement in mainstream health research in England a decade after policy implementation? A realist evaluation. *Journal of health services research & policy*, *23*(2), 98-106.

Williams, C. (2023). ‘Corridor care’in the emergency department: managing patient care in non-clinical areas safely and efficiently. *Emergency Nurse*, *31*(6).

Wind, G. (2008). Negotiated interactive observation: Doing fieldwork in hospital settings. *Anthropology & Medicine*, *15*(2), 79-89.

Wise, J. (2025). Scale of NHS’s “corridor care” is revealed in Royal College of Nursing report.

Woolf, N. H., & Silver, C. (2017). *Qualitative Analysis Using NVivo: The Five-Level QDA® Method*. Routledge.

Wolverson, E., Moniz-Cook, E., Dunn, R., & Dunning, R. (2022). Family carer perspectives on the language of behaviour change in dementia: an online mixed methods survey. *Age and Ageing*, *51*(3), afac047.

Wong Shee, A., Phillips, B., Hill, K., & Dodd, K. (2014). Feasibility and acceptability of a volunteer-mediated diversional therapy program for older patients with cognitive impairment. *Geriatric Nursing, 35*(4), 300-305.

World Health Organization (WHO). (2020). *Preventing and Managing COVID-19 Across Long-Term Care Services* (Policy Brief). WHO. https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1

World Health Organisation (WHO). (2024). *The top ten casues of death*. https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death

Yalden, J., McCormack, B., O'Connor, M., & Hardy, S. (2013). Transforming end-of-life care using practice development: an arts-informed approach in residential aged care. *International Practice Development Journal*. *3*(2), 1-18.

Yaghmour, S. M. (2022). Impact of settings and culture on nurses' knowledge of and attitudes and perceptions towards people with dementia: An integrative literature review. *Nursing Open*, *9*(1), 66-93.

Yevchak, A., Fick, D. M., Kolanowski, A. M., McDowell, J., Monroe, T., LeViere, A., & Mion, L. (2017). Implementing nurse-facilitated person-centered care approaches for patients with delirium superimposed on dementia in the acute care setting. *Journal of Gerontological Nursing, 43*(12), 21-28.

Yıldızhan, E., Ören, N., Erdoğan, A., & Bal, F. (2019). The burden of care and burnout in individuals caring for patients with Alzheimer's disease. *Community Mental Health Journal*, *55*, 304-310.

Young, J., Murthy, L., Westby, M., Akunne, A., & O'Mahony, R. (2010). Diagnosis, prevention, and management of delirium: summary of NICE guidance. *BMJ, 341*, c3704.

Zandee, D. P., & Cooperrider, D. L. (2008). Appreciable worlds, inspired inquiry. *The Sage handbook of action research: Participative Inquiry and Practice*, 190-197.

Zazzara, M. B., Penfold, R. S., Roberts, A. L., Lee, K. A., Dooley, H., Sudre, C. H., Welch, C., Bowyer, R. C., Visconti, A., Mangino, M., Freidin, M. B. (2021). Probable delirium is a presenting symptom of COVID-19 in frail, older adults: a cohort study of 322 hospitalised and 535 community-based older adults. *Age and Ageing*, *50*(1), 40-48.

Zazzara, M. B., Ornago, A. M., Cocchi, C., Serafini, E., Bellelli, G., & Onder, G. (2024). A pandemic of delirium: an updated systematic review and meta-analysis of occurrence of delirium in older adults with COVID-19. *European Geriatric Medicine*, *15*(2), 397-406.

Zermansky, A. G., Alldred, D. P., Petty, D. R., Raynor, D. K., Freemantle, N., Eastaugh, J., & Bowie, P. 2006. Clinical medication review by a pharmacist of elderly people living in care homes—randomised controlled trial. *Age and Ageing, 35*, 586-591.

Zermansky, A. G., Alldred, D. P., Petty, D. R., & Raynor, D. K. (2007). Striving to recruit: the difficulties of conducting clinical research on elderly care home residents. *Journal of the Royal Society of Medicine, 100*, 258-261.

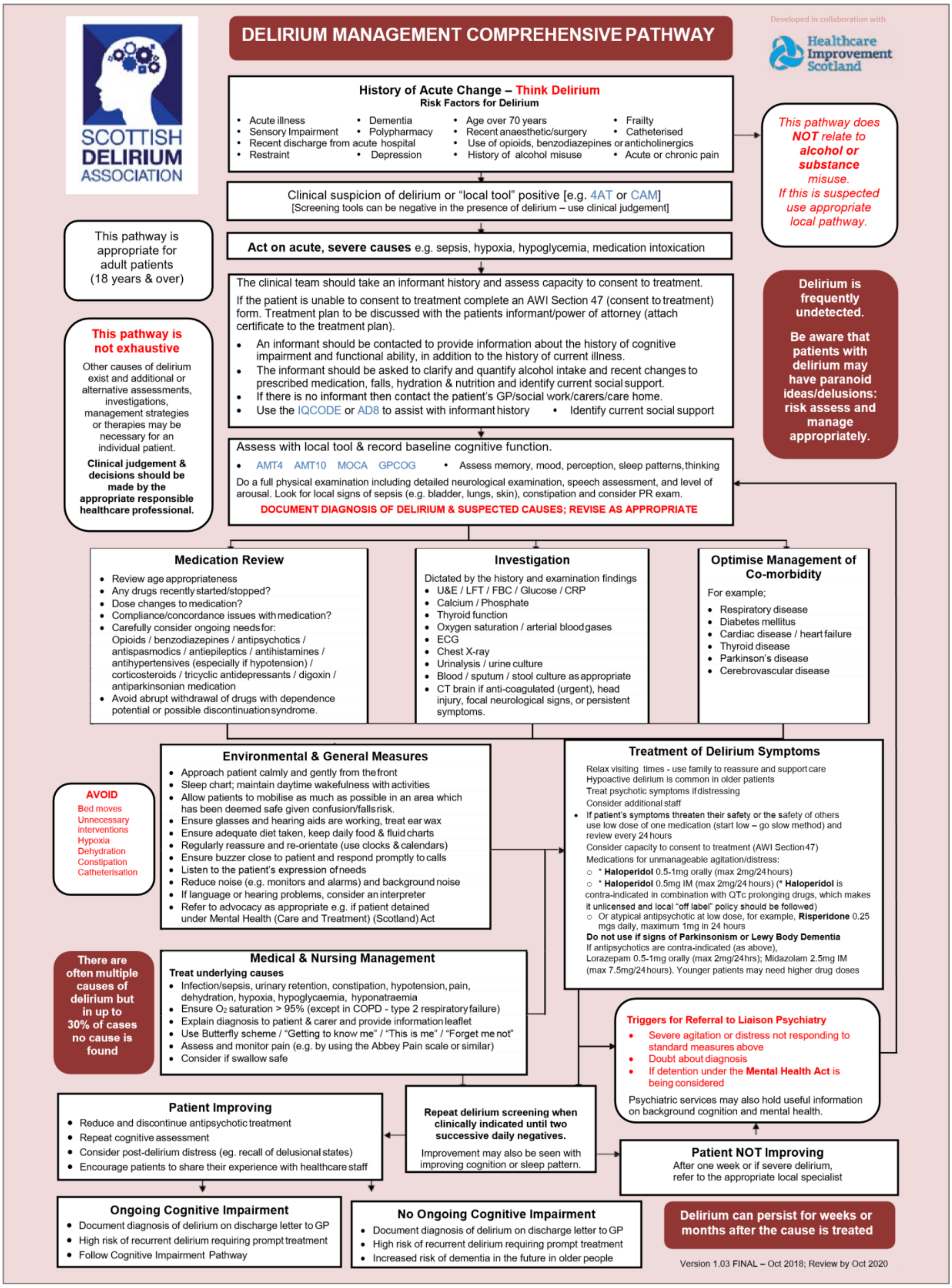
Zhou, C., Wang, H., Wang, L., Zhou, Y., & Wu, Q. (2024). Diagnostic accuracy of the Family Confusion Assessment Method for delirium detection: A systematic review and meta-analysis. *Journal of the American Geriatrics Society*, *72*(3), 892-902.

Zimmerman, S., Sloane, P. D., & Reed, D. (2014). Dementia prevalence and care in assisted living. *Health Affairs, 33*(4), 658-666.

Appendices

Appendix 1 - SIGN 157 Delirium Management

Appendix 1 SIGN 157 Delirium Management Pathway



SCOTTISH DELIRIUM ASSOCIATION

DELIRIUM MANAGEMENT COMPREHENSIVE PATHWAY

Developed in collaboration with
Healthcare Improvement Scotland

History of Acute Change – Think Delirium
Risk Factors for Delirium

- Acute illness
- Sensory Impairment
- Recent discharge from acute hospital
- Restraint
- Dementia
- Polypharmacy
- Depression
- Age over 70 years
- Recent anaesthetic/surgery
- Use of opioids, benzodiazepines or anticholinergics
- History of alcohol misuse
- Frailty
- Catheterised
- Acute or chronic pain

*This pathway does **NOT** relate to **alcohol or substance** misuse. If this is suspected use appropriate local pathway.*

Clinical suspicion of delirium or “local tool” positive [e.g. 4AT or CAM]
[Screening tools can be negative in the presence of delirium – use clinical judgement]

This pathway is appropriate for adult patients (18 years & over)

Act on acute, severe causes e.g. sepsis, hypoxia, hypoglycemia, medication intoxication

The clinical team should take an informant history and assess capacity to consent to treatment.

If the patient is unable to consent to treatment complete an AWI Section 47 (consent to treatment) form. Treatment plan to be discussed with the patients informant/power of attorney (attach certificate to the treatment plan).

- An informant should be contacted to provide information about the history of cognitive impairment and functional ability, in addition to the history of current illness.
- The informant should be asked to clarify and quantify alcohol intake and recent changes to prescribed medication, falls, hydration & nutrition and identify current social support.
- If there is no informant then contact the patient’s GP/social work/carers/care home.
- Use the IQCODE or AD8 to assist with informant history
- Identify current social support

Delirium is frequently undetected.

Be aware that patients with delirium may have paranoid ideas/delusions: risk assess and manage appropriately.

This pathway is not exhaustive

Other causes of delirium exist and additional or alternative assessments, investigations, management strategies or therapies may be necessary for an individual patient.

Clinical judgement & decisions should be made by the appropriate responsible healthcare professional.

Assess with local tool & record baseline cognitive function.

- AMT4 AMT10 MOCA GPCOG
- Assess memory, mood, perception, sleep patterns, thinking

Do a full physical examination including detailed neurological examination, speech assessment, and level of arousal. Look for local signs of sepsis (e.g. bladder, lungs, skin), constipation and consider PR exam.

DOCUMENT DIAGNOSIS OF DELIRIUM & SUSPECTED CAUSES; REVISE AS APPROPRIATE

Medication Review

- Review age appropriateness
- Any drugs recently started/stopped?
- Dose changes to medication?
- Compliance/concordance issues with medication?
- Carefully consider ongoing needs for: Opioids / benzodiazepines / antipsychotics / antispasmodics / antiepileptics / antihistamines / antihypertensives (especially if hypotension) / corticosteroids / tricyclic antidepressants / digoxin / antiparkinsonian medication
- Avoid abrupt withdrawal of drugs with dependence potential or possible discontinuation syndrome.

Investigation

Dictated by the history and examination findings

- U&E / LFT / FBC / Glucose / CRP
- Calcium / Phosphate
- Thyroid function
- Oxygen saturation / arterial blood gases
- ECG
- Chest X-ray
- Urinalysis / urine culture
- Blood / sputum / stool culture as appropriate
- CT brain if anti-coagulated (urgent), head injury, focal neurological signs, or persistent symptoms.

Optimise Management of Co-morbidity

For example;

- Respiratory disease
- Diabetes mellitus
- Cardiac disease / heart failure
- Thyroid disease
- Parkinson’s disease
- Cerebrovascular disease

AVOID
Bed moves
Unnecessary interventions
Hypoxia
Dehydration
Constipation
Catheterisation

Environmental & General Measures

- Approach patient calmly and gently from the front
- Sleep chart; maintain daytime wakefulness with activities
- Allow patients to mobilise as much as possible in an area which has been deemed safe given confusion/falls risk.
- Ensure glasses and hearing aids are working, treat ear wax
- Ensure adequate diet taken, keep daily food & fluid charts
- Regularly reassure and re-orientate (use clocks & calendars)
- Ensure buzzer close to patient and respond promptly to calls
- Listen to the patient’s expression of needs
- Reduce noise (e.g. monitors and alarms) and background noise
- If language or hearing problems, consider an interpreter
- Refer to advocacy as appropriate e.g. if patient detained under Mental Health (Care and Treatment) (Scotland) Act

Treatment of Delirium Symptoms

Relax visiting times - use family to reassure and support care
Hypoactive delirium is common in older patients

Treat psychotic symptoms if distressing

Consider additional staff

- **If patient’s symptoms threaten their safety or the** safety of others use low dose of one medication (start low – go slow method) and review every 24 hours

Consider capacity to consent to treatment (AWI Section 47)

Medications for unmanageable agitation/distress:

○ * **Haloperidol** 0.5-1mg orally (max 2mg/24 hours)

○ * **Haloperidol** 0.5mg IM (max 2mg/24 hours) (* **Haloperidol** is contra-indicated in combination with QTc prolonging drugs, which makes it unlicensed and local “off label” policy should be followed)

○ Or atypical antipsychotic at low dose, for example, **Risperidone** 0.25 mgs daily, maximum 1mg in 24 hours

Do not use if signs of Parkinsonism or Lewy Body Dementia

If antipsychotics are contra-indicated (as above),
Lorazepam 0.5-1mg orally (max 2mg/24hrs); Midazolam 2.5mg IM (max 7.5mg/24 hours). Younger patients may need higher drug doses

There are often multiple causes of delirium but in up to 30% of cases no cause is found

Medical & Nursing Management

Treat underlying causes

- Infection/sepsis, urinary retention, constipation, hypotension, pain, dehydration, hypoxia, hypoglycaemia, hyponatraemia
- Ensure O_2 saturation > 95% (except in COPD - type 2 respiratory failure)
- Explain diagnosis to patient & carer and provide information leaflet
- Use Butterfly scheme / “Getting to know me” / “This is me” / “Forget me not”
- Assess and monitor pain (e.g. by using the Abbey Pain scale or similar)
- Consider if swallow safe

Triggers for Referral to Liaison Psychiatry

- Severe agitation or distress not responding to standard measures above
- Doubt about diagnosis
- If detention under the **Mental Health Act** is being considered

Psychiatric services may also hold useful information on background cognition and mental health.

Patient Improving

- Reduce and discontinue antipsychotic treatment
- Repeat cognitive assessment
- Consider post-delirium distress (eg. recall of delusional states)
- Encourage patients to share their experience with healthcare staff

Repeat delirium screening when clinically indicated until two successive daily negatives.

Improvement may also be seen with improving cognition or sleep pattern.

Patient NOT Improving

After one week or if severe delirium, refer to the appropriate local specialist

Ongoing Cognitive Impairment

- Document diagnosis of delirium on discharge letter to GP
- High risk of recurrent delirium requiring prompt treatment
- Follow Cognitive Impairment Pathway

No Ongoing Cognitive Impairment

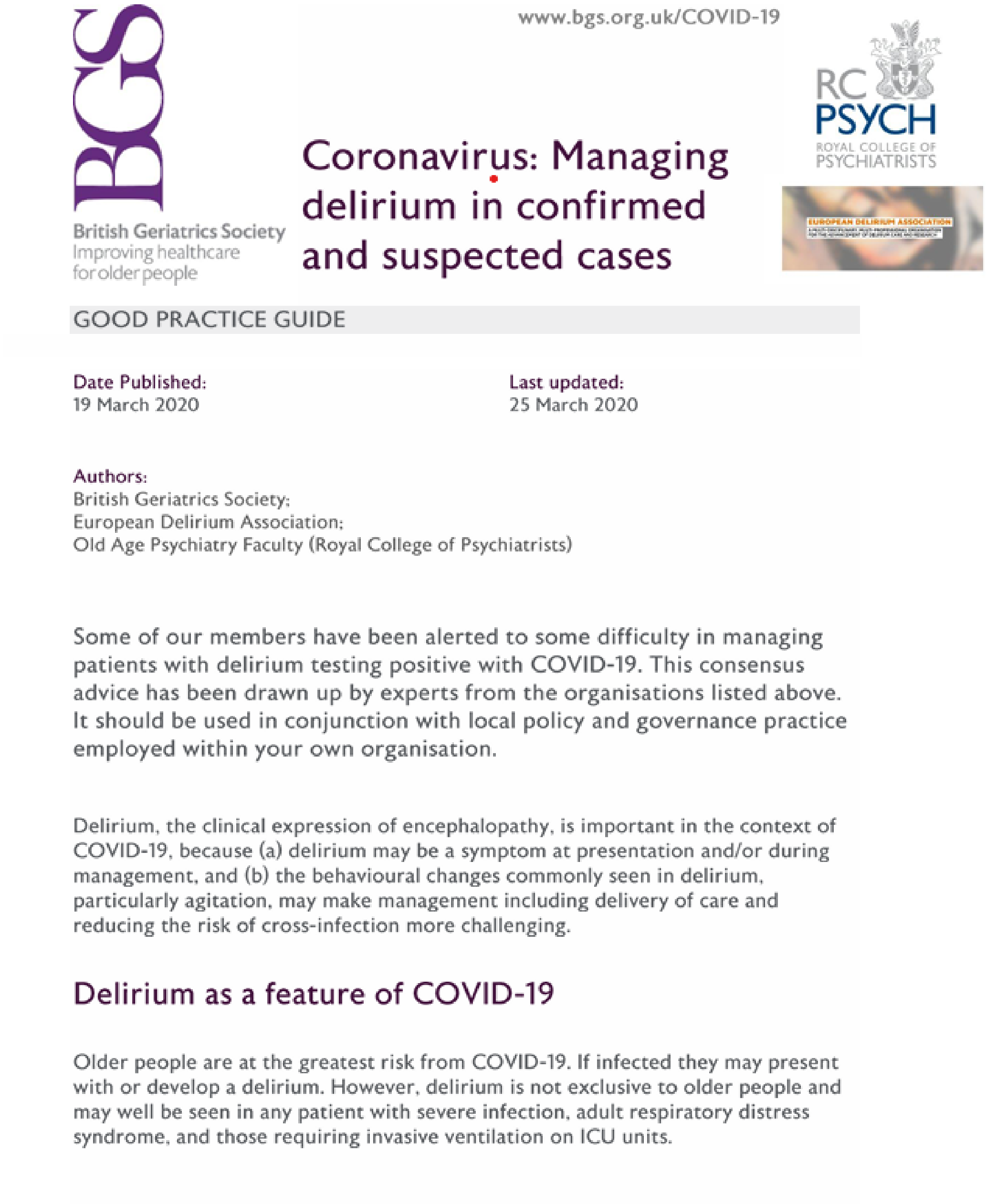
- Document diagnosis of delirium on discharge letter to GP
- High risk of recurrent delirium requiring prompt treatment
- Increased risk of dementia in the future in older people

Delirium can persist for weeks or months after the cause is treated

Version 1.03 FINAL – Oct 2018; Review by Oct 2020

Appendix 2 - British Geriatric Society Delirium Guidance

Click on the image below to view the guidance



www.bgs.org.uk/COVID-19

BGS
British Geriatrics Society
Improving healthcare
for older people

Coronavirus: Managing delirium in confirmed and suspected cases

RC PSYCH
ROYAL COLLEGE OF
PSYCHIATRISTS

EUROPEAN DELIRIUM ASSOCIATION

GOOD PRACTICE GUIDE

Date Published: 19 March 2020	**Last updated:** 25 March 2020

Authors:
British Geriatrics Society;
European Delirium Association;
Old Age Psychiatry Faculty (Royal College of Psychiatrists)

Some of our members have been alerted to some difficulty in managing patients with delirium testing positive with COVID-19. This consensus advice has been drawn up by experts from the organisations listed above. It should be used in conjunction with local policy and governance practice employed within your own organisation.

Delirium, the clinical expression of encephalopathy, is important in the context of COVID-19, because (a) delirium may be a symptom at presentation and/or during management, and (b) the behavioural changes commonly seen in delirium, particularly agitation, may make management including delivery of care and reducing the risk of cross-infection more challenging.

Delirium as a feature of COVID-19

Older people are at the greatest risk from COVID-19. If infected they may present with or develop a delirium. However, delirium is not exclusive to older people and may well be seen in any patient with severe infection, adult respiratory distress syndrome, and those requiring invasive ventilation on ICU units.

Appendix 2 British Geriatric Delirium Guidelines

1. Enhanced implementation of screening for delirium in at risk groups and also regular assessment for delirium using a recommended tool (e.g. the 4AT www.the4AT.com[1]). This may be increasingly constrained by staff and time limitations.
2. Reduce the risk of delirium by avoiding or reducing known precipitants. Actions include: regular orientation, avoiding constipation, treating pain, identification and treatment of superadded infections early, maintaining oxygenation, avoiding urinary retention and medication review. See the SIGN delirium guidance [2]
3. With respect to behavioural disturbance, always look for and treat direct causes including pain, urinary retention, constipation, etc. Where these interventions are ineffective or more rapid control is required to reduce the risk of harm to the patient and others, it may be necessary to move to pharmacological management earlier than would normally be considered. In these circumstances we would recommend the guidance provided in the SIGN guidance[2], but in more urgent situations would advise referring to the NICE Guidance on Violence and Aggression[3].
4. If patients are treated using the NICE rapid tranquillisation interventions, please monitor for side effects, vital signs, hydration level and consciousness at least every hour until there are no further concerns about the person's physical health. Be mindful of use of benzodiazepine with respiratory depression. In older adults note the British National Formulary maximum dosage for haloperidol is 5mg in 24 hrs, but we would suggest a more conservative approach with maximum 2mg in 24 hours in the first instance. Where higher dosages are required, please seek specialist advice.
5. Note the usual guidance of caution with use of medication in older people, and especially certain medications in people with Parkinson's disease or dementia with Lewy bodies (e.g. antipsychotic medication)
6. Delirium may cause considerable distress amongst both staff and families in addition to the patient. Provision of information around delirium is important using locally available resources. Booklets are available through the SIGN website: https://www.sign.ac.uk/pat157-delirium[4]

Appendix 3 - Link to SIGN Guidelines

1. Download the quick reference guide here

Appendix 4 - Prospero

Providing care for patients with dementia and delirium in the acute hospital setting: a protocol for a systematic review

Citation: Caroline Ashton-Gough, Claire Goodman, Jennifer Lynch. Providing care for patients with dementia and delirium in the acute hospital setting: a protocol for a systematic review. PROSPERO 2019 CRD42019130369 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019130369

Review question

What kind of organisational, educational and peer support is required to deliver an improved nurse-carer relationship for delirium prevention in hospital in patients with dementia?

What is the evidence that approaches that involve patients with Delirium Superimposed on Dementia (DSD), nurses and their relatives/supporters lead to improved outcomes for the patient and experience for the carer?

Searches

Relevant studies will be identified by searching electronic databases:

*PubMed

PsycINFO via OVID

*CINAHL

*Cochrane Library

A free web search (Google Scholar) will be conducted additionally as well as a search of relevant journals. The search strategy will be available on request from the author. Date restriction will be February 2009-December 2019. Language will be restricted to English. The searches will be re-run just before the final writing up and further studies completed for inclusion.

All citations identified by the searches will be downloaded into an Endnote database. CA will independently screen the titles and abstracts against the inclusion criteria with at least 10% done by two reviewers against the predefined inclusion criteria. Discrepancies will be identified and resolved through discussion. Types of study to be included.

The following search terms will be used in combination with Boolean operators AND/OR and with truncations where necessary. The terms will be used as database specific controlled vocabulary where available and additionally as unspecified search terms.

“Cognition disorders” (MeSH), Cognitive ADJ3 impairment (MeSH), “Cognitive impairment” (MeSH), “Cognitive disorder” (MeSH), (cognitive ADJ3 disorder”), Cognition disorders OR Cognitive Impairment OR Cognitive disorder OR Cognition disorders

Dementia (MeSH), (dementia), Dementia (MeSH) OR dementia

Delirium (MeSH), (delirium), Delirium (MeSH) OR (delirium)

“Cognition disorders” (MeSH), Cognitive ADJ3 impairment (MeSH), “Cognitive impairment” (MeSH), “Cognitive disorder” (MeSH), (cognitive ADJ3 disorder”), Cognition disorders OR Cognitive Impairment OR Cognitive disorder OR Cognition disorders OR Dementia (MeSH), (dementia), Dementia (MeSH) OR dementia

“HOSPITALS, District” (MeSH), (hospital*), “HEALTH CARE FACILITY ENVIRONMENT” (MeSH), (ward*)

“HOSPITALS OR, District” (MeSH), OR (hospital*), OR “HEALTH CARE FACILITY ENVIRONMENT” (MeSH), OR (ward*)

“GERIATRIC ASSESSMENT” (MeSH), (Comprehensive geriatric assessment**), (RAID), (Rapid Assessment
Integrated Discharge*), (Comprehensive geriatric assessment**), OR (RAID), OR (Rapid Assessment Integrated Discharge*)

Types of study to be included

Included papers will be categorised by study design e.g.: randomised-controlled trial, controlled trial, before/after study (with or without control), cohort study (with or without concurrent controls), case control, survey, process evaluation and qualitative study. Process evaluations will be categorised in terms of the interventions’ implementation, its acceptability, and the explanations about whether an intervention was successful or unsuccessful. Non-intervention studies will be distinguished by how patients with DSD were identified, who provided the care (e.g. Nurses, Unqualified staff, Volunteers, multidisciplinary team), how family carers were involved and how information about the older persons preferences and biography were used. Data will be extracted on the intervention, the characteristics of the participants and the providers, the country, the main aims of the study, and the outcome measures. Limited to English language, articles published from March 2009 - December 2019.

Condition or domain being studied

Dementia and specifically the care of patients with delirium superimposed on dementia in the hospital setting.

Dementia describes the symptoms of a large group of neurodegenerative illnesses. It is used to describe a loss of memory, intellect, rationality, social skills and physical functioning. Dementia affects almost 50 million people worldwide, which is predicted to increase to 131.5 million by 2050.

Delirium is a common, serious but often treatable condition that starts suddenly in someone who is unwell. Delirium is defined as an acute impairment in cognition and a disturbance in awareness and attention. Delirium is four times more likely to occur in hospitalised older adults with dementia. Anyone can get delirium; the following risk factors place someone at higher risk:

- Having a previous cognitive impairment/dementia
- Being over 65
- Being frail or having multiple medical conditions
- Visual or sensory impairment
- Being on multiple medications (for example, antipsychotics, benzodiazepines)

Delirium and delirium superimposed on Dementia is a significant issue for older hospitalised patients. People with delirium superimposed on dementia risk an increased length of hospital stay, institutionalisation and mortality. Nurses working with family carers have the potential to improve patients with dementia's experience of care and reduce adverse outcomes.

Participants/population

Inclusion criteria included: 1) hospital in-patients with dementia (all types and stages) or cognitive impairment, (2) inpatients with delirium superimposed on dementia/cognitive impairment, 3) patients with dementia identified as at risk of developing delirium, 4) volunteers who can represent the needs of the patient, (5) nurses in hospital who care for people with dementia and delirium, (6) formal/informal care-givers of people with dementia/delirium and (7) studies involving the multidisciplinary team, i.e. doctors, healthcare assistants, Allied Health Professional (AHP) who work with patients with dementia and superimposed delirium.

Exclusion criteria included: 1) conducted with older people with dementia and delirium in a long term or community setting and 2) older people without a diagnosis of dementia or cognitive impairment.

Intervention(s), exposure(s)

Training interventions for nurses working in hospitals working with people with dementia and at risk of delirium or with delirium.

Interventions or training for nurses working with family carers to improve the outcomes of people with dementia and at risk of delirium or with delirium including studies that adopt a person-centred/relationship centred/human rights approach to care.

Observational and participatory design to improve working between nurses and family carers to improve the outcomes of people with dementia and at risk of delirium or with delirium.

Comparator(s)/control

None.

Context

Inpatient hospital settings.

Main outcome(s)

Patient experience and satisfaction including quality of care.

Carer experience.

Resource Use.

Additional outcome(s).

None.

Data extraction (selection and coding)

Tile and abstracts initially screened by the primary researcher (CA) to determine studies that met the inclusion criteria. Full texts of potentially eligible, articles will then be reviewed. When inclusion of studies is unclear against the protocols criteria the articles will be screened by the additional researchers (CG, JL). A PRISMA diagram will be used to identify the phases of inclusion and exclusion of the data. All articles selected will be stored in the reference software end note.

Data from included studies will be extracted into a MS Excel form. The first author (CA) will extract data based on participant's characteristics.

Data to be extracted: author, year of publication, country of study, study aims and objectives, study design and methods, setting, study population, intervention evaluated or described, role of the professional involved, documented outcomes, generalisability of results, inclusion/exclusion criteria.

Risk of bias (quality) assessment

The first researcher will independently review all articles for inclusion. If necessary, the additional researcher/s will review based on the study protocol. This review is guided by the assumption of a systematic review. This detailed review is likely to inform the need for primary research.

The Cochrane Collaboration risk of bias tool and Spencer et al.'s quality assessment checklist for qualitative studies will be used to assess the methodological quality of qualitative, quantitative and mixed methods research.

Strategy for data synthesis

As the study design is not limited to RCTs, there will be a mixture of experimental and qualitative articles for review and likely to be a low homogeneity of results. Therefore, included papers will be synthesised using an inductive narrative synthesis to present the learnings from the review. Analysis will be informed by theories of person centred/relationship centred care and the rights of people living with dementia.

Analysis of subgroups or subsets

The review questions will be answered through narrative analysis of data extracted. The heterogeneity of the aims and approach of the literature being reviewed means it is unlikely that there will be scope to complete a meta-analysis.

Contact details for further information

Caroline Ashton-Gough

carolineashton@googlemail.com

Organisational affiliation of the review

University of Hertfordshire

Review team members and their organisational affiliations

Mrs Caroline Ashton-Gough. University of Hertfordshire

Professor Claire Goodman. University of Hertfordshire

Dr Jennifer Lynch. University of Hertfordshire

Type and method of review

Intervention, Methodology, Narrative synthesis, Synthesis of qualitative studies, Systematic review

Anticipated or actual start date

08 April 2019

Anticipated completion date

30 September 2019

Funding sources/sponsors

None.

Conflicts of interest

Language

English

Country

England

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Delirium; Dementia; Humans

Date of registration in PROSPERO

24 April 2019

Date of first submission

07 April 2019

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

Stage of review at time of this submission

The review has not started

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

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Appendix 5 - Study Quality - qualitative studies

Joanna Briggs Institute Critical Appraisal Tool for Qualitative Research (Lockwood et al., 2015)

Questions

2. Is there congruity between the stated philosophical perspective and the research methodology?
3. Is there congruity between the research methodology and the research questions or objectives?
4. Is there congruity between the research methodology and the methods used to collect data?
5. Is there congruity between the research methodology and the representation and analysis of the data?
6. Is there congruity between the research methodology and the interpretation of the results?
7. Is there a statement locating the researcher culturally or theoretically?
8. Is the influence of the researcher on the research, and vice-versa addressed?
9. Are participants, and their voices, adequately represented?
10. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
11. Do the conclusions draw on the research report flow from the analysis, or interpretation, of the data?

Citation	Study design	JBI critical appraisal questions													Overall
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	
Ayton et al. (2019)	Mixed Method	Y	Y	Y	Y	Y	N	N	Y	Y	Y	N/A	N/A	N/A	Include
Bateman et al. (2016)	Quasi-Experimental	Y	Y	Y	N	N	Y	Y	Y	Y	U	N/A	N/A	N/A	Include
Blair et al. (2018)	Mixed Methods	Y	Y	Y	N	N	Y	Y	Y	Y	Y	N/A	N/A	N/A	Include
Boltz et al. (2015)	Comparative Repeated Measures study	Y	Y	Y	N	N	N	N	U	Y	Y	N/A	N/A	N/A	Include
Collier et al. (2020)	Qualitative	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N/A	N/A	N/A	Include
Fick et al. (2011)	Prospective Cohort	Y	Y	Y	N	N	Y	N	Y	U	Y	N/A	N/A	N/A	Include
Kang et al. (2017)	Mixed Methods	N	Y	Y	Y	N	N	U	U	Y	Y	N/A	N/A	N/A	Include

Mailhot et al. (2020)	Validation	Y	Y	Y	Y	U	N	N	Y	U	Y	N/A	N/A	N/A	Include
Paulson et al. (2016)	Qualitative	Y	Y	U	U	Y	N	N	Y	Y	Y	N/A	N/A	N/A	Include
Teodorczuk et al. (2014)	Grounded Theory	Y	Y	Y	Y	Y	N	N	N	Y	Y	N/A	N/A	N/A	Include
Wong Shee et al. (2014)	Qualitative	Y	Y	Y	U	U	N	N	Y	N	Y	N/A	N/A	N/A	Include
Yevchak et al. (2017)	Exploratory Descriptive	Y	Y	Y	U	Y	N	N	U	Y	Y	N/A	N/A	N/A	Include

Key: Y = yes; N = no; U = unclear; N/A = not applicable

Appendix 6 - Study Quality RCT

Joanna Briggs Institute Critical Appraisal Tool for RCT (Tufanaru et al., 2020)

Questions

1. Was true randomisation used for assignment of participants in treatment groups?
2. Was allocation to treatment groups concealed?
3. Were treatment groups similar at the baseline?
4. Were participants blind to treatment alignment?
5. Were those delivering treatment blind to treatment assignment?
6. Were outcomes assessors blind to treatment alignment?
7. Were treatment groups treated identically rather than the intervention of interest?
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?
9. Were participants analysed in the groups to which they were randomised?
10. Were outcomes measured in the same way for treatment groups?
11. Were outcomes measured in a reliable way?
12. Was appropriate statistical analysis used?
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups accounted for in the conduct and analysis of the trial?

Citation	Study design	JBI critical appraisal questions													Overall
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	
Goldberg et al. (2013)	RCT	N	Y	Y	Y	N	U	N	Y	Y	Y	Y	Y	Y	Include
Martinez et al. (2012)	RCT	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	N	Y	Include
Waszynski et al. (2018)	RCT	Y	Y	Y	N/A	Y	Y	Y	N	Y	Y	Y	Y	Y	Include

Key: Y = yes; N = no; U = unclear; N/A = not applicable

Appendix 7 - Intervention Characteristics

Table 3 Study Characteristics

Author, year and location	Study design and setting	Number of participants, age and condition	Type of family carer Intervention	Comparison/ Control and Duration of data collection	How Dementia and delirium was assessed	Outcomes measured
Ayton et al., 2020 Australia	Mixed methods. Acute and sub-acute metropolitan hospital (Pre implementation study)	Nurses (N=73) (returning surveys) patient/ caregiver dyad interviews (N=4) Key stakeholder interviews (Consultant, OT, Volunteer coordinator etc.) (N=7) Condition- Dementia/ Delirium	1:1 companionship for patients with dementia and/or delirium provided by volunteers	Not reported	Not reported	Acceptability of the programme for key stakeholders - patients, caregivers, nurses, hospital staff and volunteers.
Bateman et al. (2016) Australia	Quasi-experimental; pre-post design. Acute rural hospital	Patients Aged> 65 years |(or> 50 years for Aboriginal persons) (N= 64) Dementia/ delirium Diagnosis, known risk factors for Delirium or SMMSE< 25/30	Volunteer training programme; including completion of personal profile with the patient or family carer	Data collected at baseline and at 8 months	A diagnosis of dementia OR A Diagnosis of Delirium OR Mini Mental State Examination (SMMSE) score of<25/30 OR one or more risk or precipitating factors for delirium	Patient Outcomes: Use of Antipsychotics/ Psychotropic Medications Use of analgesia Use of antidepressants Length of stay, Number of falls Incidence of delirium Staff/Volunteer Outcomes

						Staff: Attitude to PCC Volunteers: knowledge and confidence. Attitude to PCC.
Blair et al. (2018) Australia	Non-randomised controlled trial. Seven acute rural Hospitals located in Southern New South Wales local health district (SNSWLHD).	Patients (N=270) Family members (N=80) staff (survey) (N=119) Staff (focus groups) (N=46) volunteers (N=44). Patients had dementia or delirium Condition- Dementia and/or delirium	Volunteer training programme Completed a Personal Profile with the family carer Family interviews/ surveys Focus groups	Control group of historical patients admitted 12 months prior to programme. Beginning of Project (data recorded over 8 months)	Not reported	Increased safety, and quality of care. Increased patient well-being. Reduction in family care burden. Reduction in nursing care burden.
Boltz et al., 2015 USA	Comparative repeated measures study. Five medical units in two hospitals in Northeast USA.	Patients (Older adults aged 65 or over) English speaking/ reading; a positive mini-cog; Intervention group N=44; Non-intervention group n=42. Family caregiver N=86 Dyads.	A function focused model of care intervention including 4 components, (1) environmental and policy assessment, (2) staff education, (3) individualised goals, (4) motivation of nursing staff/patients.	One intervention unit in each hospital, three control units Over 18 months	A positive mini-cog assessment	Patient outcomes: ADL performance; walking performance; gait and balance; delirium severity; hospital discharge outcomes. Family caregiver measures: preparedness for care-giving; anxiety and depression; strain; mutuality between caregiver and care receiver

Collier et al., 2020 Australia	Qualitative, using video reflexive ethnography. Specialist older people and evaluation management unit in a sub-acute hospital.	Patients (n = 3); family members (n = 5); managerial staff members (n = 2); clinical staff members (n = 35); and nonclinical staff members (n = 5). Age-not reported Condition-dementia and delirium	Observation of patients, family and staff members.	21 months	Not reported	Team commitment to high quality fundamentals of care. Teamwork. Dementia-friendly environment. Aptitude to working with people with dementia.
Fick et al., 2011 USA	Prospective cohort pilot study testing feasibility of one component of multicomponent intervention. One adult medical surgical unit in an acute care hospital	Patients n=15 Patients /Family N=3 Aged over 65, mean age 83. Dementia diagnosis	Computerised decision support screen (for delirium assessment and management) component of multicomponent intervention for early nurse detection of delirium superimposed on dementia. Study followed consecutively admitted patients and their caregivers for duration of admission.	Study carried out over 14-week period Patients and family carers followed for duration of hospital stay	Aged 65 and over, met criteria for dementia using MBDRS screen. Family caregiver was interviewed using two instruments Modified Blessed Dementia Rating scale and Clinical Dementia Rating Scale. Daily assessment of delirium using a structured interview consisting of MMSE, Observation, and the Confusion Assessment	Nurse adherence to and usability of electronic medical record documentation. Narrative feedback on screens. Patient and family satisfaction surveys post discharge.

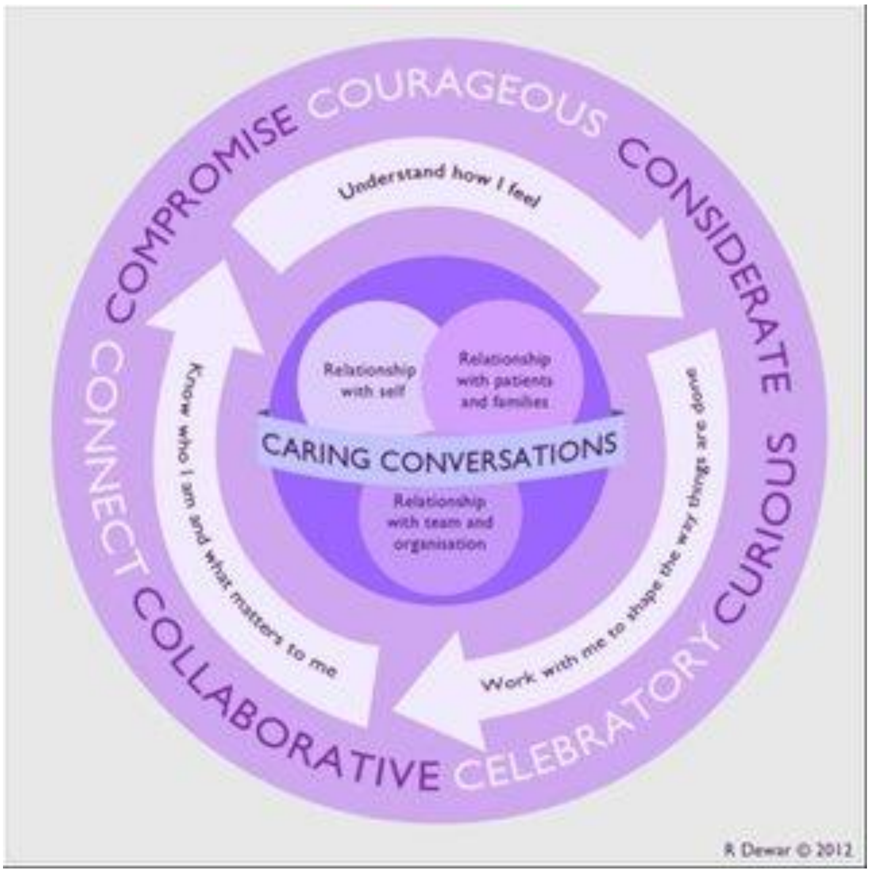
					Method (CAM).	
Goldberg et al., 2013 England	Randomised controlled trial. Large acute general hospital in the UK Medical/Mental health unit (28 beds)	N=600 patients (310 from specialist unit, 290 from standard care) n=250 sets patient notes Age over 65yr. Patients with dementia and/or delirium	Family carers were recruited, if available and willing to act as an informant. Proactive and inclusive approach to family carers	Randomised to either usual care ward or specialist medical and mental health unit. Recruitment over 18 months Follow up completed at month 21.	Not recorded. Patients included identified as ‘confused’ on admission (mitigating overlap in delirium and dementia) but not requiring other specialist care.	Number of days spent at home (or in the same care home) in the 90 days after randomisation. Quality of life. Behavioural and psychological symptoms. Physical disability. Cognitive impairment (MMSE); Inpatient falls. Mortality. Patient experience. Length of stay. Carer strain. Carer wellbeing. Carers’ satisfaction.
Kang et al., 2016 South Korea	Mixed methods sequential explanatory, pre-post design. One regional general hospital	RNs N=40 recruited for education programme. Purposive sample of RNs N=12 Family Caregivers N=6 No patients recruited.	Individual interviews. Delirium brochures given to family caregivers as part of nurse education programme	Conducted between July 2013 and March 2014. RNs completed surveys at baseline and 3 months after the educational programme Qualitative interviews, 2 months after the programme	Not reported	Impact of education programme. Nurses’ knowledge of cognitive impairment. Attitudes to older adults. Nurse initiated efforts to involve family caregivers.

Martinez et al., 2012 Chile	Single-blind randomised controlled trial. Internal medicine ward	Patients N=287 Age->70 years Condition- previous history of cognitive impairment	Non-pharmacological intervention delivered to and by family members, including education on delirium; avoidance of sensory deprivation; presence of familiar objects; provision of clock and calendar in the room; reorientation of patient by family; extended visitation times.	Standard care (N=143). Allocated to multicomponent intervention (N=144). Patients recruited over 8 months with follow-up until last hospital discharge.	All patients at risk of delirium on basis of 1 risk factor <24 on mini-mental state examination	Presence of delirium assessed by CAM. Incidence of falls during hospital stay and complications derived from them.
Mailhot et al., 2020 USA	Validation study. Urban academic emergency department (ED).	Dyads of ED patients aged 70 and older and their family caregivers (N=108 dyads). Condition- with/without dementia	Family caregiver self-administered the family confusion assessment method (FAM-CAM) independently.	For concurrent validity, performance of the FAM-CAM was compared to the reference-standard confusion assessment method (CAM). For predictive validity, clinical outcomes over 6-months were compared by FAM-CAM status (positive /negative)	The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) used for caregiver assessment of the patient's level of cognitive functioning.	Performance characteristics of the FAM-CAM method. Clinical outcomes 6 months post enrolment by FAM-CAM status: ED visits, hospitalization and mortality.
Paulson et al., 2016 USA	Education initiative implementation within large multisite intervention study.	Nurses (N=32) and ancillary staff (N=14) given brochure. Nurses (N=7) completed	Delirium education brochure for family caregivers. Shared with nurses to be	implemented over 16 months	Patient data not included	Nurse feedback on use and usefulness of a delirium education brochure for

	24 bedded inpatient medicine and Acute Care of the Elderly unit (ACE) at a large medical centre	feedback survey. No patients recruited	used with family caregivers			family carers and staff.
Teodorczuk et al., 2014 UK	Implementation and evaluation study. One regional hospital Trust.	Health care professionals (N=48) representing 12 different professional groups. No patients recruited.	Training programme underpinned by learning from patients and family carers	2-day interprofessional dementia and delirium education programme. Course implemented 3 times over 18-month period	Patient data not recorded	Participants' confidence in certain acts of professionalism related to care of confused older patients. Changes in attitudes and knowledge.
Waszynski et al., 2018 USA	Single site randomised controlled trial. Mixed factorial design. Acute care, level 1 trauma centre in an inner-city state	Hospitalised patients with dementia experiencing delirium (N=126) Family members (N=56) participated in the production of family video messages.	Family members recruited to produce video message	Family video intervention compared to nature video intervention and usual care. Intervention x 4 time points, Conducted over 9 months.	Hyperactive or mixed delirium evidenced by positive score on CAM, and a score of >0 Richmond Agitation Sedation Scale (RASS), Dementia assessment not recorded.	Medication administration for decreasing agitation. Participant agitation (ABS score).
Wong Shee et al., 2014 Australia	Qualitative design. 30 bed Inpatient rehabilitation unit, large regional health service	Patients (N= 30) Carers (N= 3) Volunteers (N=10) Staff (N=6)	Volunteer diversional therapy programme	Study conducted over 6 months.	Cognitive impairment, defined as a Mini Mental State Examination (MMSE) score <25 25 or a diagnosis of dementia, and had exhibited behavioural disturbance (e.g. agitation or wandering)	Staff, volunteers and patients/ carers perceptions (acceptability and feasibility) of intervention.
Yevchak et al., 2017	Qualitative, exploratory, descriptive	Patients (N=803)	Weekly delirium rounds led by advanced	Analysis of delirium	Not reported	Instances of person-centred

USA	study within cluster randomised trial. Across 3 regional and academic medical centre sites.	51.4% of delirium rounds included research staff and unit champion Number of family carers not reported Patients with dementia and/or delirium	practitioner nurse (N=750). Staff were encouraged to talk with patients and family members to learn more about hobbies, interests and occupation.	rounds over 38 months.		care during delirium rounds.

Appendix 8 - Caring Conversations



R Dewar © 2012

Macbride et al., 2014. Using an appreciative stance in practice development

Appendix 9 - Ethics

Prof Claire Goodman
Professor of Health Care Research
University of Hertfordshire
College Lane, Hatfield
Hertfordshire
AL10 9AB

Email:
approvals@hra.nhs.uk

05 September 2022

Dear Prof Goodman

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Caring for hospital patients with delirium superimposed on dementia and their family carers: an appreciative inquiry**
IRAS project ID:	**280075**
REC reference:	**22/EE/0144**
Sponsor	**University of Hertfordshire**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **280075**. Please quote this on all correspondence.

Yours sincerely,

Vic Strutt

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Annah Whyton* **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Response to ethical review document]	1	27 July 2022
Copies of materials calling attention of potential participants to the research [Invitation Poster]	2	16 April 2022
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Insurance]		06 August 2021
Interview schedules or topic guides for participants [Interview Schedule, Staff]	1	18 June 2022
Interview schedules or topic guides for participants [Interview Schedule, Family Carers]	1	18 June 2022
Interview schedules or topic guides for participants [Interview Schedule (Patient)]	1	16 June 2022
IRAS Application Form [IRAS_Form_21062022]		21 June 2022
Letter from sponsor [Sponsorship]	1	11 April 2022
Organisation Information Document [Organisational Information Document]	2	18 June 2022
Other [Response to HRA specialist]		
Participant consent form [Staff]	4	24 August 2022
Participant consent form [Consultee Declaration Form]	3	24 July 2022
Participant consent form [Personal consultee declaration form (clean)]	4	21 July 2022
Participant consent form [Nominated consultee declaration form (clean)]	5	21 July 2022
Participant consent form [Participant Consent Form]	4	19 June 2022
Participant consent form [Relative/Participant Consent Form]	3	20 June 2022
Participant consent form	4.0	21 July 2022

[Personal+Consultee+Declaration+form+v4]		
Participant information sheet (PIS) [Participant Information Sheet]	3	21 July 2022
Participant information sheet (PIS) [Participant+information+sheet+(patient)+v3]	3.0	21 July 2022
Participant information sheet (PIS) [Accessible Patient Information Sheet]	3	26 July 2022
Participant information sheet (PIS) [Nominated Consultee Information Sheet]	2	21 July 2022
Participant information sheet (PIS) [Relative or Friend PIS]	4	24 August 2022
Participant information sheet (PIS) [Staff PIS]	3	24 August 2022
Participant information sheet (PIS) [Personal consultee information sheet]	2	16 April 2022
Research protocol or project proposal	10	24 August 2022
Schedule of Events or SoECAT [Schedule of Events]	1	18 June 2022
Summary CV for Chief Investigator (CI) [CV for chief investigator v 1]	CV Chief Investigator	06 June 2022
Summary CV for student	1	24 May 2022
Summary CV for supervisor (student research)		
Summary CV for supervisor (student research) [CV]	1	16 June 2022
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Study Design Flow chart]	1	24 May 2022

Appendix 10 - Study invitation poster

IRAS project ID	**280075**

We are looking for staff and family carers who have cared for a person with dementia and delirium to take part in an exciting study!

The study, led by a dementia Clinical Nurse Specialist/ researcher, its aim at exploring the experiences and approaches that support the relationship-centred care of a person with dementia at risk of or who develops delirium

- Are you a carer/family member who is 18 years or over?
- Are you a member of staff supporting patients in the acute setting

The findings from this study will contribute to the very limited published information about the relationship centred approaches that support the care of people living with dementia at risk of developing or diagnosed with delirium currently available.

The goal is to use the results from this study to inform health care professionals and give them a greater understanding of what the experience of delirium superimposed on dementia may be. This will hopefully enable them to provide better levels of support for patients and their families.

If you would like to participate in this research, you would be taking part in an interview that would take approximately one hour. This interview can either be face-to-face with the researcher at a comfortable and convenient place and time of your choosing or, if you prefer, the interview can be conducted by telephone, video or email.

To learn more about this study, please email Caroline Ashton- at caroline.ashton5@nhs.net. I would be grateful to hear from you by May 2021. Thank you for reading about this research.

University of Hertfordshire UH

Appendix 11 - Participant Information Sheet

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS (‘ETHICS COMMITTEE’)

FORM EC6: PARTICIPANT INFORMATION SHEET-PATIENT

1 Title of study

Establishing the human connection in dementia and delirium care

2 Introduction

Princess Alexandra Hospital NHS Trust and the University of Hertfordshire would like to invite you to take part in a research study taking place from November 2020 to March 2021. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about it if you wish (my version).

OR

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University’s regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(After accessing this website, scroll down to Letter S where you will find the regulation).

Thank you for reading this.

3 What is the purpose of this study?

The purpose of this research study is to find out what things affect your experiences of receiving care and what could be done to support you while in hospital. We are interested to know how being in hospital affected your normal routine, whether you felt at times more disorientated during your hospital stay. Your experience as a patient and what has helped you to feel safe and what particular approaches the staff caring for you have taken are important to us. In this study we want to learn more about what it feels like to be a person with dementia and delirium in hospital and how to support people to ensure that is a core part of all our work.

4 Do I have to take part?

It is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive.

5 Are there any age or other restrictions that may prevent me from participating?

There are no age restrictions preventing you from participating. You need to have a diagnosis of dementia.

6 How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for the following time frames

15-20 minutes to consent

45-60 minutes for the first interview

20 minutes to review the transcription to check on our interpretation of what was said in the first interview

7 What will happen to me if I take part?

We are asking patients to take part in a number of ways, which may include (it is not anticipated that you will be involved in all the activities, but you will be asked in the consent form to indicate those you feel happy in).

Observation of your care

We hope to observe the care you receive from staff whilst in hospital. One of the researchers (also a trained nurse) will work alongside staff when they are providing your care. Observing in this way will ensure minimal disruption to the care given to you and other patients. The researchers will observe for periods of up to two hours. It is anticipated that each period of observation will involve a different group of patients. For example, a group of patients may include 8 patients located in one bay of the ward, therefore you would not be observed for the whole period. Whilst observing your care, we will respect your right to dignity and privacy.

8 What are the possible disadvantages, risks or side effects of taking part?

We will be discussing issues about your experience of receiving care. As part of this we will be discussing your views on what effects the care had on you. Some participants could find this causes distress or upset. We want to make sure this research works well for everyone taking part and will do our best to support all participants. This could include any assistance or comfort you need or want to help you during our discussions, as well as someone to talk to afterwards. We will check with you if you need anything to help you take part and ensure that this support is provided.

9 What are the possible benefits of taking part?

We will be working closely with hospital staff to make sure we all learn from this project. Whilst we cannot promise that taking part will help you directly, the information we get from this research will help to improve care and enhance the education programmes for all staff in relation to dementia and delirium care. We have found in other projects that staff have reported benefits and have learned a great deal in project work.

10 How will my taking part in this study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. The interviews and observations will be taking place in the hospital in a quiet place away from the ward - others may know you have taken part, however all information we obtain will be treated in confidence and personal reference, and identifying information will be removed.

All information collected during the research will be held either in a research office at the University of Hertfordshire or a locked cabinet in a locked office. A small number of staff will have access to the information held (these people are listed on page). Professor Claire Goodman as the Chief Investigator will act as custodian of this information and will ensure that it is kept in a confidential and secure way, in accordance with the Data Protection Act, 1998.

Information from audio recordings and observations will be entered on to a secure (password protected) computer system. All information being entered will be coded; no names and addresses will be entered with this information. Your position will be identified, for example if we use a quote from you, we could put the word “patient” beside it.

If you do give your name and contact details, this information will be held in a separate computer file on a secure (password protected) computer system. Written information such as consent forms will be held in locked cabinets at the study site.

You can view copies of any information held on you at any time on request. All information will be kept securely for 5 years, then destroyed confidentially.

We will not share any personal information held on you at any time on request. All information will be kept securely for 5 years, then destroyed confidentially.

We will not share any personal information that you have given us with any other organisations.

<Applicant: please enter details here; please also indicate how any personal data on the completed consent form will be stored; the points in items 12 and 13 should be addressed in determining what you will do with the consent forms and the information they contain, together with the period over which you intend to store them>

11 **Audio-visual material**

We will not be creating any audio- visual material.

12 **What will happen to the data collected within this study?**

<Applicant: this section relates to the Section on Confidentiality and Consent in Form EC1. In this section you must include details of how the data collected will be used in this study. Should you encounter any issues during the study, you should consult with your supervisor. Please note that you must adhere to the arrangements indicated by you in the Application Form EC1.>

<please delete statements below that do not apply>

- The data collected will be stored electronically, in a password-protected environment, for <> months, after which time it will be destroyed under secure conditions.

- The data collected will be stored in hard copy <by me> <by the University> in a locked cupboard for <> months/years, after which time it will be destroyed under secure conditions.

- The data will be anonymised prior to storage.

- The data will be transmitted/displayed <explain how, where, when, whether identities will be revealed>.

- You will be asked to sign a 'Contributors' Release Form' to allow the transmission of the audio/visual material to which you have contributed.

13 Will the data be required for use in further studies?

The results of this research will be published and shared with participants and other individuals and organisations involved with or who have an interest in the research. Participants will not be identified in any reports produced, without their prior consent. The results will also be used to inform future service and educational developments.

<Applicant: this section relates to the Section on Confidentiality and Consent in Form EC1 and relates to how long the data will be kept and whether it will be re-used>.

- The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised.

- The results of the study and/or the data collected (in anonymised form) may be deposited in an open access repository.

14 Who has reviewed this study?

This study has been reviewed by:

<Please delete whichever does not apply:>

- The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

or

- The University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee with Delegated Authority

The UH protocol number is <*enter*>

15 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

16 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email: Caroline Ashton-Gough, Dementia Team, Princess Alexandra Hospital, Hamstel Road, Harlow, Essex, CM20 1QX, 01279 278233, caroline.ashton5@nhs.net

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS (‘ETHICS COMMITTEE’)

FORM EC6: PARTICIPANT INFORMATION SHEET-RELATIVE/CARER

The Princess Alexandra Hospital and the University of Hertfordshire would like to invite you to take part in a research study taking place from November 2020 to March 2021. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to others about it if you wish.

1 Title of study

Establishing the human connection in dementia and delirium care

2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University’s regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 What is the purpose of this study?

The purpose of this research study is to find out from patients and their carers/relatives or friends their experiences of dementia and delirium care in the acute hospital setting. Your experience as a relative/friend of someone who is in the hospital, or has been a patient at the hospital, and what could be done to help improve dementia and delirium care across PAH is important. In this study we want to learn more about what it feels like to be alongside a person with dementia and delirium and how to support people to ensure that is a core part of all our work.

To summarise the study proposes to:

To establish what is the evidence that approaches that involve patients with delirium superimposed on dementia (DSD), nurses and their relatives and supporters lead to improved outcomes for the patient and experience for the carer.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

5 Are there any age or other restrictions that may prevent me from participating?

There are no age restrictions preventing you from participating.

You will need to have supported a relative or friend who has dementia and may have experience delirium.

6 How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for the following time frames:

15-20 minutes to consent

45-60 minutes for the first interview

20 minutes to review the transcription to check on our interpretation of what was said in the first interview.

7 What will happen to me if I take part?

We are asking relatives/carers/friends to take part in interviews. We will also approach relatives where a patient is unable to give consent.

Being interviewed

You will be asked to take part in two interviews. The interviews will be conducted by the researcher from the University of Hertfordshire who is also a member of PAH trust staff. The interview will last for around 45-60 minutes and you will be asked about your experience of caring for patients with dementia and delirium. You will be asked about your thoughts in relation to compassionate, person-centred care and how you communicate with family members and how this might help the care of the patients on your ward.

The interviewer will ask questions about

- First realising something was wrong
- How experiencing your relative/friend distressed made you feel
- Being in the ward
- Getting better
- Communication
- Going home

The second interview will take 20 minutes and will involve the researcher feeding back and checking with you, their understanding of what you said. If you are agreeable, these interviews will be recorded.

Observations of your relative’s care

For patients who are able to give consent, we would approach them directly to seek their permission.

One of the researchers (a trained nurse) will work alongside staff when they are providing your relative's care. Observing in this way will ensure minimal disruption to the care given to your relative and other patients. The researchers will observe for periods of up to two hours. It is anticipated that each period of observation would involve a different group of patients. For example, a group of patients may include 8 patients located in one bay of the ward, therefore your relative would not be observed for the whole two-hour period. Whilst observing your relative's care we will respect their right to privacy and dignity.

The purpose of observing care is to give us a fuller picture and assist us in our overall understanding of person centred/relationship centred care. Information from observations of care will be considered alongside interviews with patients, relatives and staff.

8 What are the possible disadvantages, risks or side effects of taking part?

We will be discussing issues about your experiences of supporting a person with dementia/delirium. Some participants could find this causes distress or upset. We want to make sure this research works well for everyone taking part and will do our best to support all participants. This could include any assistance or comfort you need or want to help you during our discussions, as well as someone to talk to afterwards. We will check with you if you need anything to help you take part and ensure that this support is provided.

9 What are the possible benefits of taking part?

We will be working closely with hospital staff to make sure we all learn from this project. Whilst we cannot promise that taking part will help you directly, the information we get from this research will help to improve care and enhance the education programmes for all staff in relation to dementia and delirium care. We have found in other projects that staff have reported benefits and have learned a great deal in project work.

10 How will my taking part in this study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. While the meeting will take place in the hospital in a quiet place away from the ward - others may know you have taken part, however all information we obtain will be treated in confidence and personal reference and identifying information will be removed.

All information collected during the research will be held either in a research office at the University of Hertfordshire or a locked cabinet in a locked office. A small number of staff will have access to the information held (these people are listed on page). Professor Claire Goodman as the Chief Investigator will act as custodian of this information and will ensure that it is kept in a confidential and secure way, in accordance with the Data Protection Act, 1998.

Information from audio recordings and observations will be entered on to a secure (password protected) computer system. All information being entered will be coded; no names and addresses will be entered with this information. Your position will be identified, for example if we use a quote from you, we could put the words “relative” beside it.

If you do give your name and contact details, this information will be held in a separate computer file on a secure (password protected) computer system. Written information such as consent forms will be held in locked cabinets at the study site.

You can view copies of any information held on you at any time on request. All information will be kept securely for 5 years, then destroyed confidentially.

We will not share any personal information held on you at any time on request. All information will be kept securely for 5 years, then destroyed confidentially.

We will not share any personal information that you have given us with any other organisations.

<Applicant: please enter details here; please also indicate how any personal data on the completed consent form will be stored; the points in items 12 and 13 should be addressed in determining what you will do with the consent forms and the information they contain, together with the period over which you intend to store them.>

11 **Audio-visual material**

Not applicable for this study

<If you are intending to create audio-visual material, the participant must be informed of this. Items 12 and 13 should be completed to describe what will happen to this form of recording data, in terms of both storage and its transmission/display, and whether it might be required for use in further studies.>

12 What will happen to the data collected within this study?

<Applicant: this section relates to the Section on Confidentiality and Consent in Form EC1. In this section you must include details of how the data collected will be used in this study. Should you encounter any issues during the study, you should consult with your supervisor. Please note that you must adhere to the arrangements indicated by you in the Application Form EC1.>

<please delete statements below that do not apply>

- The data collected will be stored electronically, in a password-protected environment, for <> months, after which time it will be destroyed under secure conditions.

- The data collected will be stored in hard copy <by me> <by the University> in a locked cupboard for <> months/years, after which time it will be destroyed under secure conditions.

- The data will be anonymised prior to storage.

- The data will be transmitted/displayed <explain how, where, when, whether identities will be revealed.>

- You will be asked to sign a 'Contributors' Release Form' to allow the transmission of the audio/visual material to which you have contributed.

13 Will the data be required for use in further studies?

<Applicant: this section relates to the Section on Confidentiality and Consent in Form EC1 and relates to how long the data will be kept and whether it will be re-used.>

<please delete statements below that do not apply.>

- The data will not be used in any further studies.

<**OR>**

- The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised.

- The results of the study and/or the data collected (in anonymised form) may be deposited in an open access repository.

14 Who has reviewed this study?

This study has been reviewed by:

<Please delete whichever does not apply:>

- The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

or

- The University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee with Delegated Authority

The UH protocol number is <*enter*>

15 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

16 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email: caroline.ashton5@nhs.net, 01279 278233 Dementia Team C/O Princess Alexandra Hospital , Hamstel Road, Harlow, Essex, CM20 1QX.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC6: PARTICIPANT INFORMATION SHEET- STAFF

1 Title of study

Establishing the human connection in dementia and delirium care

2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(After accessing this website, scroll down to Letter S where you will find the regulation).

Thank you for reading this.

3 What is the purpose of this study?

The purpose of this research study is to find out from patients and their carers/relatives or friends their experiences of dementia and delirium care in the acute hospital setting. Your experience as a staff member who is working in the hospital and what current interventions support compassionate patient centred dementia and delirium care, and what could be done to help support that care. In this study we want to learn more about what it feels like to be alongside a person with dementia and delirium and how to support people to ensure that is a core part of all our work.

To summarise

To establish what is the evidence that approaches that involve patients with delirium superimposed on dementia (DSD), nurses and their relatives and supporters lead to improved outcomes for the patient and experience for the carer.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive (should this be relevant).

5 Are there any age or other restrictions that may prevent me from participating?

There are no age restrictions preventing you from participating.

You will need to work in a patient facing role and have regular contact with patients with dementia and delirium.

6 How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for the following time frames:

15-20 minutes to consent

45-60 minutes for the first interview

20 minutes to review the transcription to check on our interpretation of what was said in the first interview.

7 What will happen to me if I take part?

The first thing to happen will be

We are asking staff to take part in interviews and to give consent to the research team observing care giving practices on the ward.

Being interviewed

You will be asked to take part in two interviews. The interviews will be conducted by the researcher from the University of Hertfordshire who is also a member of PAH trust staff. The interview will last for around 45-60 minutes, and you will be asked about your experience of caring for patients with dementia and delirium. You will be asked about your thoughts in relation to compassionate, person-centred care and how you communicate with family members and how this might help the care of the patients on your ward.

The second interview will take 20 minutes and will involve the researcher feeding back and checking with you, their understanding of what you said. If you are agreeable, these interviews will be recorded.

8 What are the possible disadvantages, risks or side effects of taking part?

(Note: if appropriate for this particular study, you will be asked to agree to any required health screening questionnaire in advance of the study. Please also note that circumstances may arise that could result in the need for you to withdraw from the study; should such circumstances occur, the investigator will discuss the matter with you.)

We will be discussing issues about your experiences of giving care. Some participants could find this causes distress or upset. We want to make sure this research works well for everyone taking part and will do our best to support all participants. This could include any assistance or comfort you need or want to help you during our discussions, as well as someone to talk to afterwards. We will check with you if you need anything to help you take part and ensure that this support is provided.

9 What are the possible benefits of taking part?

We will be working closely with hospital staff to make sure we all learn from this project. Whilst we cannot promise that taking part will help you directly, the information we get from this research will help to improve care and enhance the education programmes for all staff in relation to dementia and delirium care. We have found in other projects that staff have reported benefits and have learned a great deal in project work.

10 How will my taking part in this study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in part 2. While the meeting will take place in the hospital in a quiet place away from the ward - others may know you have taken part, however all information we obtain will be treated in confidence and personal reference and identifying information will be removed.

All information collected during the research will be held either in a research office at the University of Hertfordshire or a locked cabinet in a locked office. A small number of staff will have access to the information held (these people are listed on page). Professor Claire Goodman as the Chief Investigator will act as custodian of this information and will ensure that it is kept in a confidential and secure way, in accordance with the Data Protection Act, 1998.

Information from audio recordings and observations will be entered on to a secure (password protected) computer system. All information being entered will be coded; no names and addresses will be entered with this information. Your position will be identified, for example if we use a quote from you, we could put the words “staff member” beside it.

If you do give your name and contact details, this information will be held in a separate computer file on a secure (password protected) computer system. Written information such as consent forms will be held in locked cabinets at the study site.

You can view copies of any information held on you at any time on request. All information will be kept securely for 5 years, then destroyed confidentially.

We will not share any personal information held on you at any time on request. All information will be kept securely for 5 years, then destroyed confidentially.

We will not share any personal information that you have given us with any other organisations, **except** in the following exceptional circumstances: if information is disclosed by you that leads us to believe that someone is at significantly risk of harm or abuse, information may be passed to relevant authorities. You would be informed of this.

<Applicant: please enter details here; please also indicate how any personal data on the completed consent form will be stored; the points in items 12 and 13 should be addressed in determining what you will do with the consent forms and the information they contain, together with the period over which you intend to store them.>

11 Audio-visual material

<If you are intending to create audio-visual material, the participant must be informed of this. Items 12 and 13 should be completed to describe what will happen to this form of recording data, in terms of both storage and its transmission/display, and whether it might be required for use in further studies.>

12 What will happen to the data collected within this study?

<Applicant: this section relates to the Section on Confidentiality and Consent in Form EC1. In this section you must include details of how the data collected will be used in this study. Should you encounter any issues during the study, you should consult with your supervisor. Please note that you must adhere to the arrangements indicated by you in the Application Form EC1.>

<please delete statements below that do not apply>

- The data collected will be stored electronically, in a password-protected environment, for <> months, after which time it will be destroyed under secure conditions.

- The data collected will be stored in hard copy <by me> <by the University> in a locked cupboard for <> months/years, after which time it will be destroyed under secure conditions.

- The data will be anonymised prior to storage.

- The data will be transmitted/displayed <explain how, where, when, whether identities will be revealed.>

- You will be asked to sign a 'Contributors' Release Form' to allow the transmission of the audio/visual material to which you have contributed.

13 Will the data be required for use in further studies?

<Applicant: this section relates to the Section on Confidentiality and Consent in Form EC1 and relates to how long the data will be kept and whether it will be re-used.>

<please delete statements below that do not apply.>

- The data will not be used in any further studies.

<**OR>**

- The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymised.

- The results of the study and/or the data collected (in anonymised form) may be deposited in an open access repository.

14 Who has reviewed this study?

This study has been reviewed by:

<Please delete whichever does not apply:>

- The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

or

- The University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee with Delegated Authority

The UH protocol number is <*enter*>

15 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

16 Who can I contact if I have any questions?

If you would like further information, or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email:

Caroline Ashton-Gough c/o Princess Alexandra Hospital Hamstel Road, Harlow, Essex, CM20 1QX.

caroline.ashton5@nhs.net

01279-278233

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix 12 - Consent Forms

To be completed by researcher
Participant ID_______________

Caring for people

with dementia and delirium in hospital

Staff Consent Form

This consent form is for the 'Caring for people with dementia and delirium' study. Please read the below statements, tick the box next to each and then sign to confirm you have understood and agree to participate. The first section is for all participants, you need to tick to confirm understanding of these statements. The second section is to take part in observations. The third section is to take part in interviews. The fourth section is to take part in focus groups. You can take part in observations, interviews or focus groups. Please tick the boxes in each of the sections that you wish to take part in and sign at the end of the document.

		Tick
1	I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.	☐
2	I understand that taking part in this study is my choice and that I am free to withdraw without giving a reason.	☐
3	I understand that if I choose to withdraw from the study, information already collected will be kept and used for the study.	☐

4 I agree for my details and a copy of this form to be stored by the researcher at The University of Hertfordshire for the purposes of this study. ☐

5 I agree to allow information collected from this study to be used for further research on the understanding that I will remain anonymous. ☐

6 I agree to take part in this study. ☐

Observations:

Please tick each statement to show you have read it and agree

7 I agree to be observed and for the researcher to collect data about me during their observations. ☐

8 I understand I can ask the researcher to stop the observation at any time without giving a reason. ☐

9 I understand that quotes from observation notes may be included in study outputs and agree for these to be used. I understand these will not include my name. ☐

Interviews:

Please tick each statement to show you have read it and agree.

10	I agree to take part in an interview that will be audio recorded and transcribed.	☐
11	I understand I can ask the researcher to stop the interview at any time without giving a reason.	☐
12	I understand that direct quotes from interviews may be included in study outputs and agree for these to be used. I understand that any publication will not contain any information that will enable a reader to identify the participant.	☐

Optional Questions

Job role ---

I identify my gender as (please circle correct response):

Male
Female
Genderqueer/non-binary

Please circle the number range representing your Age Range:

18-24
25-34
35-44
45-54
55-64
65 and over

Participant

My name (block capitals):..

....

Signature:...

....

Date:..

Researcher

I have explained the study to the above-named participant who has indicated their willingness to participate.

Name (block capitals):..

....

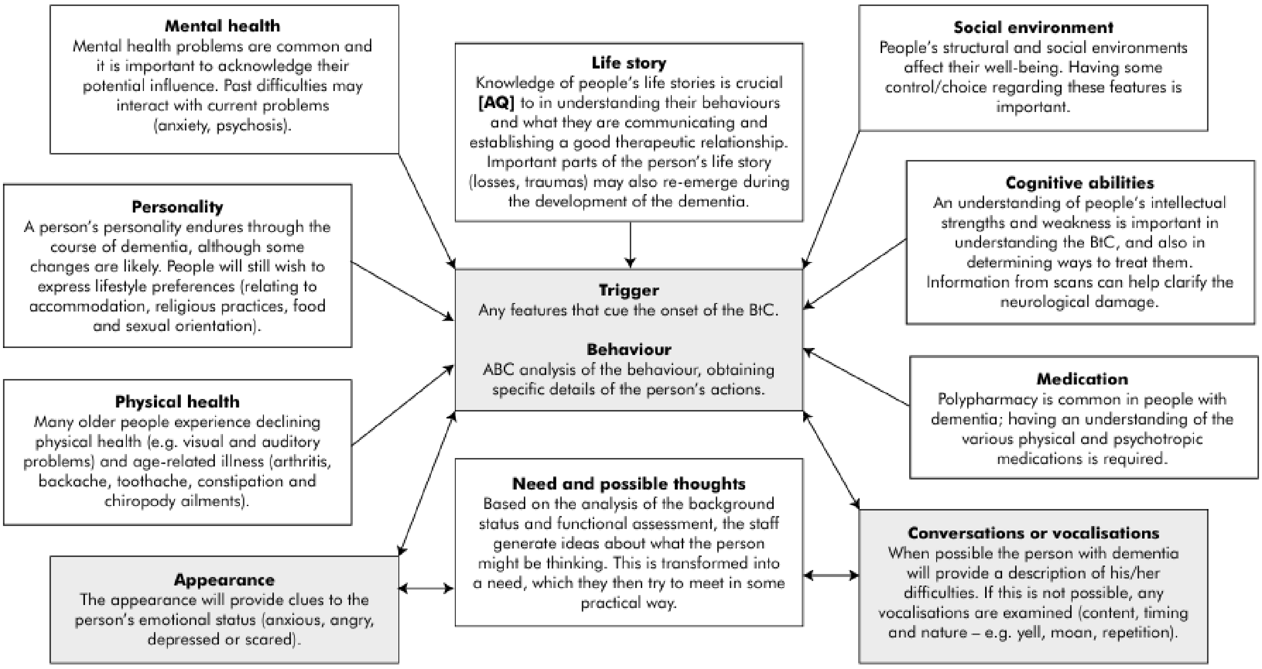
Signature:...

....

Date:..

....

Appendix 13 - Newcastle Model



Mental health
Mental health problems are common and it is important to acknowledge their potential influence. Past difficulties may interact with current problems (anxiety, psychosis).

Personality
A person's personality endures through the course of dementia, although some changes are likely. People will still wish to express lifestyle preferences (relating to accommodation, religious practices, food and sexual orientation).

Physical health
Many older people experience declining physical health (e.g. visual and auditory problems) and age-related illness (arthritis, backache, toothache, constipation and chiropody ailments).

Appearance
The appearance will provide clues to the person's emotional status (anxious, angry, depressed or scared).

Life story
Knowledge of people's life stories is crucial **[AQ]** to in understanding their behaviours and what they are communicating and establishing a good therapeutic relationship. Important parts of the person's life story (losses, traumas) may also re-emerge during the development of the dementia.

Trigger
Any features that cue the onset of the BtC.

Behaviour
ABC analysis of the behaviour, obtaining specific details of the person's actions.

Need and possible thoughts
Based on the analysis of the background status and functional assessment, the staff generate ideas about what the person might be thinking. This is transformed into a need, which they then try to meet in some practical way.

Social environment
People's structural and social environments affect their well-being. Having some control/choice regarding these features is important.

Cognitive abilities
An understanding of people's intellectual strengths and weakness is important in understanding the BtC, and also in determining ways to treat them. Information from scans can help clarify the neurological damage.

Medication
Polypharmacy is common in people with dementia; having an understanding of the various physical and psychotropic medications is required.

Conversations or vocalisations
When possible the person with dementia will provide a description of his/her difficulties. If this is not possible, any vocalisations are examined (content, timing and nature – e.g. yell, moan, repetition).

Newcastle model- James (   )

Appendix 14 - Summary of Interviews/emotional touchpoints

To be completed by researcher
Participant ID_______________

Caring for people

with dementia and delirium in hospital

Interview Schedule (Patients)

Note: Interview questions will be shaped by an appreciative inquiry approach using emotional touchpoints.

Individual interviews using a story telling approach will be carried out with patients living with dementia. A method that will help the patient to recount their experience of being in hospital. Stories are seen as an appropriate method to use, a way of revealing a meaning and ambiguity of everyday situations. Telling stories is fundamental for human thinking.

Through stories, the patient will be asked to take part in a conversation with me to share their experience of a time when **they received good care.** It may be necessary to revise this question to that of a time when they **were satisfied with care**.

A broad open-ended question will be asked at the start of the interview that invites the patient to talk about their experience:

1. Tell me about a time when you felt pleased or satisfied with the care you received from any of the hospital staff.
2. On this ward, what is it that helps you to feel more reassured?
3. In hospital, what made you feel cared for?

Using emotional touchpoints can help us to learn about the experience of patients, relatives and staff. We can learn about the things that worked well for them. The touchpoints help the storyteller to share their experience in a structured way. The information gleaned from the story can be used to identify small improvements that can have a huge impact on how care is provided and people's sense of well-being.

The emotional touchpoints that may be used in the interview will be:

Happy
Sad
Lonely
Bored
Activity
Family

Mealtimes
Medicine time
Being here at night
Taking to staff
Being with other patients
The environment
Having visitors

To help support the interview with patients the use of a photo of hospital staff could be included.

To be completed by researcher
Participant ID_______________

Caring for people with dementia and delirium in hospital

Interview Schedule (Family Carers)

Note: Interview questions will be shaped by an appreciative inquiry approach using emotional touchpoints

Individual interviews using a story telling approach will be carried out with family carers. A method that helps family carers to recount their experience of supporting a person with delirium superimposed on dementia (DSD) is important. Stories are seen as an appropriate method to use, a way of revealing a meaning and ambiguity of everyday situations. Telling stories is fundamental for human thinking.
Through stories, family carers will be asked to take part in a conversation with me to **share their experience of a time** when they experienced good care for their family member. It may be necessary to revise this question to that of a time when they **were satisfied with care**.
This method will help the interviewer and the interviewee focus directly on the emotion.

Taking each emotional touchpoint in turn, the family carer (storyteller) will be asked to select from the emotional words those that best summed up for them how their experience felt.
The emotional words will include the following:

Happy
Sad
Angry
Pleased
Being involved in care
The care of your relative
Visiting times

If a more structured approach with the use of questions is needed, then the two open-ended questions below will be used:

4. Tell me about a time when you felt pleased or satisfied with the care your family member received.
5. What do you feel works well when staff are providing care for patients with dementia and delirium?

Appendix 15 - Excerpts from reflective diary

1. My heart broke tonight, I felt totally overwhelmed emotionally and challenged professionally. I witnessed a patient deteriorate before my eyes and in my head knowing I was there in a researcher role, not a professional one and certainly not in nurse Caroline role, but I feel sad that the system, the standard of care and the recognition of distress in dementia and delirium challenged me to intervene. The letter written by his family said " keep fighting dad ", (page in Thesis) has really affected me. I also wonder if our patient's families know just how much all of this has affects us too. But, I felt we had let this gentleman down and wondered what I was doing here. He was unshaven, many days of growth, I really do get frustrated about this, why is it acceptable, is this not part of personal care. The gentleman is clearly approaching end of life, yet dignified care at the end is not happening here. He was getting out of bed, in response to massive blood loss. Isolated in a Bay of 4 with the door closed, he can't call for help, probably wouldn't be able to. The housekeeper is collecting trays around him, she seems detached from it, not engaging with the distress. I wonder if doing this was the right decision, are my supervisors really understanding how difficult this would be for me, I wonder if it is a test, I feel this takes real courage to do this. If a student asks me in the future about my research methods I will be honest and ensure that they are prepared for the emotions

2. It felt really lonely tonight, the ward I have been on is a respiratory ward, and there are still some memories of the height of COVID-19 times visible around the ward. The poster on the wall about visiting is out of date.

   Sometimes I wonder if I am too emotional to do this job, although tonight I wasn't here to do a job but just to observe interactions. The gentleman I sat with has DSD, he was in a bay with other male patients, his bed directly opposite the toilet door. On the door is a toilet sign (dementia friendly), I feel strongly we are not delirium friendly but can we achieve this in hospital, but this really distressed him. It seemed the staff around him coming in and out all the time really did not pick up on the cause for stress but what I could say is that the 2 female nurses who came to reposition him did so with such kindness, the patient during a lucid moment also told me they were kind (I really appreciated witnessing this good practice). Kindness is as important to me as an individual and of course in my AN role, sometimes I do wonder though if I expect too much and I challenge myself over that too. Leaving this ward tonight, felt lonely, I felt I really had a deep empathy for the patient I had observed. I spoke to an ex-colleague tonight, she is a lecturer at a university, she teaches student nurses, she emphasised with how tough this was for me, she said separating the two roles for me must be so hard but felt it was a good way to really understand what practice is like, she explained she hears it so often from ST nurses that practice is poor.

3. Tonight’s observation truly taught me the importance of finding the right methodological framework and how mine, relational constructionism really fits.

   I observed an agency nurse providing 1-1 care for a male patient living with dementia.

   I really had to stop and check in with myself during these periods, I challenged my thinking, am I biased, am I expecting too much, are my standards too high, which I often feel proud of especially after all these years in the NHS. I also didn’t know who to talk to about this.

   I watched the nurse sit in front of the patient, there was a table in between them both, the bedside table. The patient kept asking for something over and over again, he kept standing up as he was saying this, only to be told immediately to sit down. His speech was not clear but he looked more and more distressed.

   The agency nurse saw me, recognised me from my job role and asked me what I was doing, so I explained. He then went on to say how difficult this patient had been, he had been with him all day, he had no break until 4 and then he had to ask. He told me about the delirium and how “he’s not making any sense”, I asked about activities, about pain, about eating and drinking, he told me, “well, that’s the job really of the staff here, I am just here to make sure he doesn’t fall.

I felt ashamed at this point, to be a nurse, but part of me also felt a responsibility to ensure dementia care is the best it can be.

4. Tonight's period really highlighted how unmet needs in dementia care lead to distress. I am observing practice in a very familiar ward tonight. I quickly noticed one lady with dementia in Bed 3, in the corner, sitting alone, crying and talking to herself. I noticed that she was responding to conversations going on around her, if a member of staff walked by and didn't notice her, this caused even more distress. She became distressed at the lady in the bed opposite her, paranoid that she as talking about her. No-one noticed this and no-one intervened, I think I counted 12 possible opportunity's to connect with her which were missed. My own moral self, reflecting internally on the code of conduct do no harm, yes I am a researcher here tonight, but I am also a nurse, I couldn't allow this to continue, so intervened. I wondered what was worse, being a researcher in an environment that is alien to you and witnessing things you may not understand, or in my situation here I feel a responsibility to everyone. I will discuss this with a colleague if I can tomorrow.
5. I sat with a lady today who told me she wanted to die, she was very distressed. My palliative care skills and knowledge has taught me to some extent how to approach this but it is never easy. Some would say, "She's had a good life", "she's old, she has dementia", but to me life is very precious, I wonder if how I responded was appropriate given my researcher role tonight, it felt a privilege though to spend that time with her and hope that I helped. I will ask the chaplain to visit, selfishly? this will give me peace of mind knowing that after I have gone there will be another person to visit.