Everyday Decisions in Care Homes: Understanding and Facilitating the Involvement of People Living with Dementia and Communication Difficulties Through Appreciative Inquiry

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Abstract

Background - Approximately 70% of the 457,000 people living in UK care homes are thought to have dementia or significant memory problems. This may mean that they need additional support with everyday decisions about their life and care. However, little is known about how people living with dementia and associated communication difficulties make and share decisions about issues that matter to them in care homes.

Methods - A systematic review of studies designed to measure, implement or explore shared everyday decision-making with cognitively impaired adults in care homes in the last 20 years was completed to identify gaps in the evidence. Studies focusing on advance decisions were excluded. Findings from the review provided the context for a modified 4D cycle of Appreciative Inquiry (AI) that was designed to engage participants in two care homes in England through observation, interviews and focus groups. Observations and participant stories of decision-making interactions were used to identify how participants could enhance shared everyday decision-making between people living with dementia and their staff and family care partners. Ethical approval reference number: 226515.

Results – The systematic review, found evidence from 19 studies, that people living with dementia like to remain involved in the decisions about their care, but that their capacity to participate and the importance of supporting this is underestimated by staff and family care partners. Participants in the AI study (15 people living with dementia and communication difficulties, 24 care staff and four family care partners) were observed for a total of 72 hours and completed 13 focus groups and 26 interviews. They demonstrated that people living with dementia and communication difficulties were regularly making and sharing everyday decisions in 20 different areas. The majority of decisions that were effectively shared entailed binary choices based on residents' preferences about food and drink, physical and social activities and aspects of personal care. In addition, there were complex decisions shared with multiple staff and family care partners over extended time periods that relied on people knowing and understanding each other well. Individuals' communication difficulties, and understanding of what shared everyday decision-making could encompass, affected how they experienced and contributed to the process. Maximising shared everyday decision-making relied on participants engaging with six activities; encouragement, communication that recognised the individual needs of the resident, offering and making choices, effective uses of time and the environment, and identifying an appropriate decision partner. Ideas arising from the AI cycle that were implemented drew mainly on ideas based on participants' stories and experiences rather than evidence from the observational data or the review. Adjustments in practice included; the presentation of food and information in a more accessible manner to support meaningful choices, a post box as an opportunity to increase written communications between residents and their care partners, new meetings between residents' and staff and 1:1 time with activity staff. The modified 4D cycle of AI was an effective research approach that promoted a high level of engagement, with all participant groups contributing to the development and implementation of interventions to enhance shared everyday decision-making in the care homes.

Conclusion – Everyday decisions are commonly made and shared by people living with dementia and communication difficulties in care homes. When care home staff prioritise processes which promote the use of multiple senses to maximise residents' involvement, it is possible to challenge routine and advance personalised approaches to care within everyday encounters. Appreciative inquiry provided a structure for people living with dementia and their staff and family care partners to recognise and share good practice as the basis for small, efficient cultural and practical changes aligned with the needs of the individuals and systems related to shared decision-making in care homes. Additional work is needed to focus on specific areas of everyday decision-making in communal care settings where there is potential to further develop engagement between residents and their staff and family care partners to extend their partnerships in the planning and delivery of care and organisational decisions.

Acknowledgements

I had little understanding of the academic and emotional challenges that this journey would bring when I started. This dissertation has taken every ounce of my perseverance, pragmatism, humility and sense of humour to complete and I am genuinely thankful for the opportunities that this venture has provided. I have loved learning to become a researcher, the people I have met, changes that it has brought to my practice and the connections that I have made along the way.

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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, who I think would have been very proud; and to Nanny Mil, Great-nanny Sue and my dear friend Julie Collings that were lost along the way.

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Abbreviations

AD	Alzheimer’s Disease
AI	Appreciative Inquiry
ARD	Alcohol Related Dementia
BIA	Best Interest Assessor
CLAHRC	Collaboration for Leadership in Applied Health Research & Care
CQC	Care Quality Commission
CSF	Care Staff - Female
CSM	Care Staff - Male
DCDS	Dementia Communication Difficulties Scale (Murphy et al., 2007)
DCM	Dementia Care Mapping (Kitwood and Bredin, 1997)
DMI	Decision-Making Involvement scale (Feinberg and Whitlatch, 2002)
DN	District Nurse
DoLS	Deprivation of Liberty Safeguards
FCP	Family Care Partner
FR	Female Resident
FRF	Female Resident’s Family Care Partner
FV	Female Visitor
IRAS	Integrated Research Application System
MCA	Mental Capacity Act
MeSH	Medical Subject Heading
MR	Male Resident
MRF	Male Resident’s Family Care Partner

MV	Male Visitor
NHS	National Health Service
NIHR	National Institute for Health Research
QOL-AD	Quality of Life in Alzheimer’s Disease (Logsdon et al., 1999)
RN	Registered Nurse
UHPiRG	University of Hertfordshire Public Involvement in Research Group
UK	United Kingdom
VaD	Vascular Dementia
WHO	World Health Organisation

Glossary

(Care) Staff	People who are paid to provide care, including health and/or social care professionals.
Care Home	A residential service that provide 24 hour onsite care with or without qualified nursing care, registered with the Care Quality Commission (Care Quality Commission, 2009).
Communication (in the context of care)	The exchange of information, thoughts and feelings using speech or other means. A two way process that requires skill and the intention to understand and convey the message that the person is both understandable and acceptable (Kourkouta and Papathanasiou, 2014).
Extended Care Setting	Any type of residential housing with onsite care provision. In addition to care homes this may include (but is not limited to) supported living (small group homes), extra care housing (individual housing with onsite care) and care villages.
Family Care Partner	A person with whom the resident has a significant relationship or who they consider to be important to them. Usually a family member or a friend.

Chapter 1 - Introduction

The aim of this thesis was to explore good practice in shared everyday decision-making with people living with dementia and communication difficulties in care homes. An appreciative lens was applied to a multi-method study design which was delivered in two phases (Figure 1). Phase 1 was a systematic review of the evidence to identify what was already known about shared everyday decision-making with people living with cognitive impairment in extended care settings. Phase 2 used the Phase 1 findings to inform a ‘4D’ Appreciative Inquiry (AI) intervention study that sought to understand and improve how everyday decisions are made and shared by people living with dementia and communication difficulties, and their staff and family care partners in care homes.

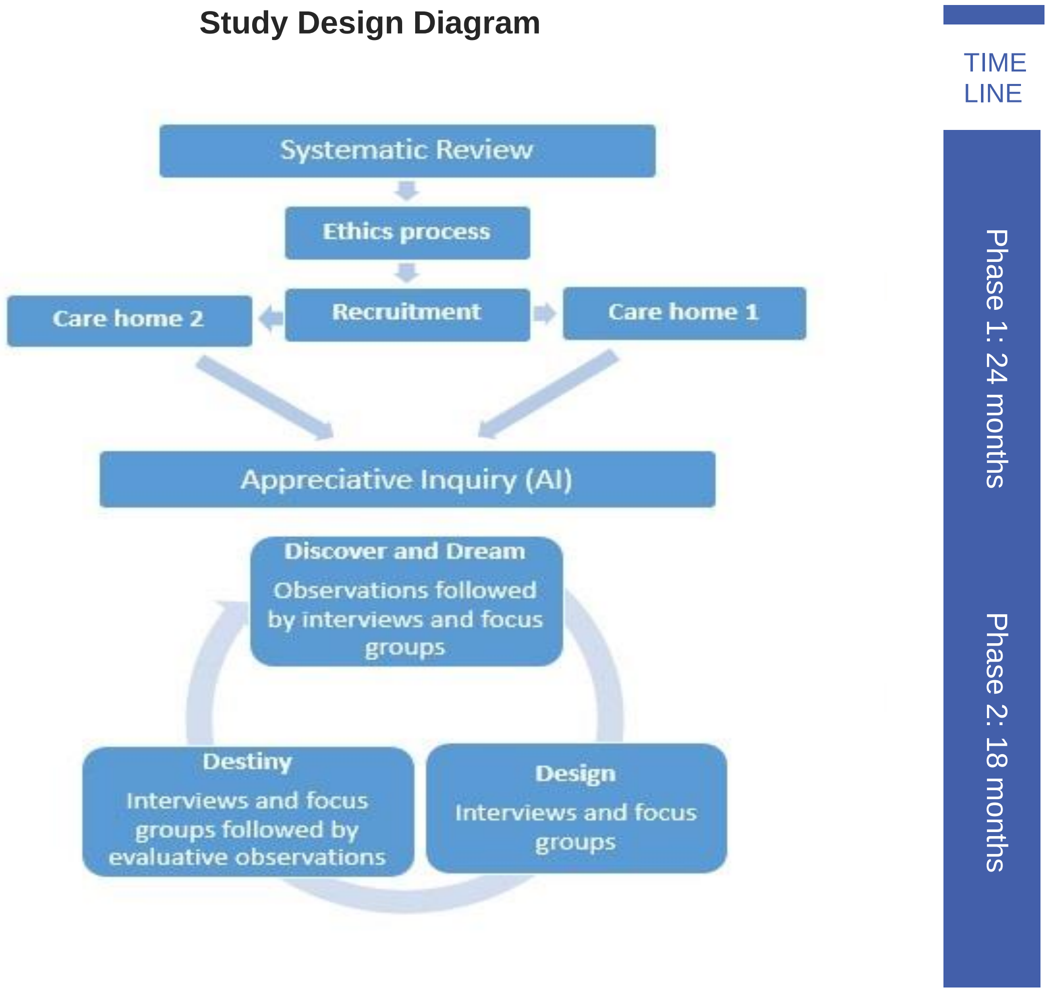

Figure 1: Study Design Diagram

Research Motivation

The primary motivation for this research was my work as a District Nurse with people living with dementia and their staff and family care partners. Care staff and family care partners appeared to be under-appreciated in supporting people living with dementia to participate in decisions about their everyday life and care, despite it being an important way of expressing personal, social, and legal independence and control (Bartlett and O'connor, 2010, Boyle, 2014, Davis et al., 2017, Menne, 2008). Difficulties experienced by people living with dementia in this area have typically been attributed to decline, and ultimately loss, of cognitive functioning (Derse, 1999, Jiménez et al., 2013). However, other research has identified that exclusion from decision-making is not always attributable to dementia related disease outcomes such as cognitive impairment alone (see e.g. Miller, 2014, Taghizadeh Larsson & Osterholm, 2014). It may instead be an indication of health and social care professionals and family care partners attempting to protect people from the burden of decision-making. However, seemingly small everyday decisions, such as what to eat or wear and how to manage personal hygiene, may be the only ways in which an individual living with dementia in a care home is able to maintain control over their daily life.

Research to improve the lives of people living in care homes is underdeveloped (National Institute for Health Research, 2017) possibly due to the particular challenges they present as communal environments and people’s own homes (Luff et al., 2015, Maas et al., 2002). In addition, care-home residents and staff can be difficult to research groups due to issues associated with; informed consent, opportunities to conduct private interviews and involvement of staff and family care partners (Hall et al., 2009, Zermansky et al., 2007, Zermansky et al., 2006), all of which may be further complicated in engaging people living with dementia in the research process.

The challenges outlined above may explain why so little is understood about shared everyday decision-making with people living with dementia in care homes. The lack of current evidence in such an important and growing area of practice motivated me to undertake work in this area. The importance of shared decision-making in personalising an individual’s care experience, promoting their independence and enhancing relationships in the social care sector is increasingly well recognised

(Department of Health, 2015a, My Home Life, 2014), as is the need to maximise an individual’s personhood and citizenship through shared decision-making (Baldwin et al., 2009, Bartlett and O'connor, 2007, Bartlett and O'connor, 2010).

This thesis considers *how* everyday decisions are understood and negotiated between people living with dementia and their staff and family care partners in care homes, as an indicator of how they experience care. In addition, it creates an opportunity for participants to share their stories and experiences to shape how shared decision-making could look and feel for them in the future. A particular focus is on how people living with dementia express their care wishes and needs despite the communication difficulties that accompany and/or compound the effects of their dementia.

Aims and Objectives

The overall aim of the study was to progress the quality and quantity of shared everyday decision-making between people living with dementia and communication difficulties, and their staff and family care partners in care homes.

The objectives of the study were:

- To determine the scope of everyday decisions that people living with dementia make and share in care homes.
- To understand what people living with dementia and communication difficulties perceive as ‘good’ shared everyday decision-making in care homes.
- To disseminate and implement ideas to enhance shared everyday decision-making opportunities for people living with dementia in extended care settings.

Initially it was hoped to use a systematic review to identify a validated shared decision-making tool that could be adapted for people living with dementia in a care home environment. No such validated tool was identified and so the study design developed as an outcome of the systematic review.

Background

Dementia

Dementia describes a collection of symptoms that are typically progressive and can include memory loss, personality changes and difficulties with cognition and visual-spatial awareness (Alzheimer's Research, 2015).

In addition to memory impairment and challenges associated with executive functioning, many people living with dementia also have communication difficulties such as aphasia or apraxia, causing such problems as dwindling vocabulary, unpredictable and disordered linguistic abilities and changes in word association (Cadieux et al., 2013, Hubbard et al., 2003). Dementia is known to affect both expressive and receptive language abilities in addition to behavioural impairments that affect communication (Potkins et al., 2003, Small and Gutman, 2002). These challenges may be compounded by sensory impairments that affect more than half of older people with cognitive impairment (Janicki and Dalton, 1998). Therefore, whilst a dementia diagnosis does not automatically render someone incapable of making a decision (Bartlett and O'connor, 2010, Wilkinson, 2001), people living with dementia may be excluded from everyday decisions about their care due to communication breakdown. However, many people living with dementia maintain a desire to communicate their values and preferences in relation to their care (Boyle, 2014, Goodman et al., 2013, Whitlatch et al., 2005, Whitlatch and Lichtenberg, 2010) - even when executive decision-making abilities are affected by cognitive changes (Boyle, 2014, Godwin, 2014, Horton-Deutsch et al., 2007, Jaworska, 1999).

There has been a significant shift in the dementia discourse, away from the medical model where an individual was considered in terms of a diagnostic label; towards a psychosocial approach, where the personhood and *experience* of the individual is central (Kitwood, 1997; Pratt & Wilkinson, 2003). As a result, psychosocial interventions are increasingly being prioritised as effective ways to support people to live well with their symptoms (Alzheimer’s Disease International, 2009).

Care Homes

Care homes offer accommodation and personal care for people who are not be able to live independently and are recognised as potentially needing support and assistance with decisions about their everyday life and care (Department of

Constitutional Affairs, 2005, The Care Act, 2014). Despite being recognised as greatly out-performing hospitals in person-centred care delivery (Care Quality Care Quality Commission, 2014), care homes are often not an individuals' first choice of place of residence. Admissions are typically triggered by a complex mix of health and social complications and progressively disabling diseases such as Alzheimer's (Baylis and Perks-Baker, 2017, Bowman and Meyer, 2014, Laing Buisson, 2017). Consequently, up to 80 per cent of the 457,000 people living in United Kingdom (UK) care homes are living with a diagnosed dementia or significant memory problems (Care Quality Commission, 2017, Demos, 2014, Prince et al., 2014, Thraves, 2016).

Approximately 84 per cent of residential care in the UK is provided by the independent sector in private (for-profit) care homes by a predominantly female workforce who are poorly paid and underqualified (Care Quality Commission, 2017, Darzi et al., 2018, Davies et al., 2014, Eborall et al., 2010, Luff et al., 2011, Luff et al., 2015). In addition, society does not value care work: It is aligned with domestic work and considered intellectually undemanding (Hussein, 2017). As a result, care staff often feel underappreciated.

All care homes in England are regulated by the Care Quality Commission (CQC) regardless of organisational ownership or funding streams (Care Quality Commission, 2009). Care homes provide residential care with or without access to 24-hour onsite nursing care. The CQC inspect services to check that every care home is: Safe, effective, caring, responsive and well-led. Inspection reports include a rating of the quality of services. Each service is rated: Outstanding, good, requires improvement or inadequate and the reports are made publicly available. Between 2014 and 2017 80 per cent of services were rated good or outstanding overall. Almost 20 per cent of services required improvement and only 2 per cent were considered to be inadequate (Care Quality Commission, 2017). The two care homes in this study were rated 'Good' and 'Outstanding' at the beginning of this study. The results of this study could therefore be transferrable to 80 per cent of care homes across the UK.

How decision-making for people living with cognitive impairment is understood and managed is affected by national legislation. In England and Wales legislation in the form of the Mental Capacity Act (MCA) (2005), the Deprivation of Liberty

Safeguards[1] (2007) (DoLS) and the Care Act (2014) work together to promote the safety and wellbeing of adults with care and support needs. However, this has placed additional pressure on care homes and their staff. For example, the way that DoLS have been applied in practice has been criticised and as a result is under review, and Section 44 of the Care Act (2014) has made wilful neglect or mistreatment of an adult who lacks capacity to make decisions a criminal offence. This has caused some care staff to become more risk averse despite evidence that eliminating risk can have a negative impact on quality of life (Meyer and Owen, 2008, Owen and Meyer, 2012).

Frameworks

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

- Shared Decision-Making,
- Mental Capacity Act (2005),
- Person-Centred Care.

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

Conceptual Framework – Shared Decision-Making

In its healthcare context, shared decision-making involves health and social care practitioners offering available care or treatment that reflects, respects and accommodates patients' preferences, values and priorities (Bunn et al., 2018a, Coulter and Collins, 2011). The concept of shared decision-making was introduced almost five decades ago as an ethical challenge to the historical medical approach to healthcare (Veatch, 1972). The term was then extended to included people with a cognitive impairment in the government document ''No decision about me without me'' (Department of Health, 2010), which captured the ambition for more 'patient' centred care practices across the National Health Service (NHS).

The work of Elwyn et al. (2003) and Span (2016) was used to frame shared decision-making for this study. These authors have emphasised the centrality of the process rather than the actual decision itself, recognising that there are multiple contexts

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[1] Currently under review

affecting how a decision is made. The assumptions guiding the design of this study included that the success (or otherwise) of the interaction and its consequences need to consider issues of ‘voice, choice and control’; including power and equality as part of everyday life in a care home setting (Bowers et al., 2009, Department of Health, 2015a, Owen et al., 2012). For people living with dementia this is extended to include how their decision making is initiated, recognised and sustained.

The ‘patient involvement in decision-making’ conceptual framework (Entwistle and Watt, 2006) reflects the complexity and importance of the involvement of the care recipient at all stages of decision-making across a range of health and care situations. The framework incorporates seven domains of patient involvement and six activities of decision-making: Recognition and clarification of a problem, identification of potential solutions, appraisal of potential solutions, selection of a course of action, implementation of the chosen course of action and evaluation of the solution adopted (Entwistle and Watt, 2006). This framework considers the psychosocial factors associated with shared decision-making along with the impact that the relationship between the ‘patient’ and the ‘clinician’ might have on the decision outcome. The framework does not however, consider how cognitive impairment associated with dementia might affect the interactions. Nor does it take account of the potential influence of care home living where interactions occur in communal environments, are subject to routines, and where documented prior preferences might take precedence over current expressed needs.

There is a lack of evidence around the impact of inter-professional shared decision-making or interactions with professions other than doctors on older people (Bunn et al., 2018b). Shared decision-making is recognised to be context specific, yet many studies take place in a clinic or hospital environment. The process of decision-making in care homes involves negotiation including those surrounding each resident (for example, staff or care partners, doctors, administrators and other residents) (High and Rowles, 1995). However, despite people living with dementia in care homes being found able to express their preferences and priorities for care, more attention could be paid to how they are included in day-to-day decision-making about their everyday wishes in extended care settings (Goodman et al., 2013) and further research has been recommended (Edvardsson et al., 2014a, Légaré and Witteman, 2013, Mariani et al., 2016, Miller et al., 2014, Stiggelbout et al., 2012).

Health and care professionals are thought to understand shared decision-making in two different ways; ‘systems’ and ‘care processes’. Systems enable the team to share decisions *about* the ‘patient’. Care processes consist of *“involvement in decision-making by patients and others significant to them by considering values, experiences, concerns and future aspirations*” (Slater et al., 2017 p.544). Slater and colleagues (2017) found that care professionals consider care processes that include the patient to be more important and effective in enhancing patient experience and quality of life than systems that make decisions about the patient. This suggests that care professionals consider directly involving people in the decisions about their everyday life and care a priority.

Shared decision-making is considered an essential aspect of person-centred care (Edvardsson et al., 2008, Mccance et al., 2011, Mccormack and Mccance, 2016, Wolfs et al., 2012) in part because it has a positive impact on a range of outcomes in the wider population, such as reduced conflict with care professionals and improved compliance with prescribed treatments (Coulter and Collins, 2011, Durand et al., 2014, Miller et al., 2014). However, definitions and expectations of shared decision-making need to diversify beyond clinical encounters. Benefits for its use in everyday situations are increasingly recognised for people living with dementia (Mariani et al., 2016, Smebye et al., 2012), with reports of reduced depressive symptoms and improved quality of life (Fetherstonhaugh et al., 2013, Menne, 2008, Stiggelbout et al., 2012, Whitlatch and Lichtenberg, 2010).

Reviews exploring the decision-making involvement of people with complex health needs, including those living with dementia, identified little relevant research related to everyday decision-making (Bunn et al., 2018a, Durand et al., 2014, Miller et al., 2014, Österholm et al., 2015). Overall, they concluded that research including community dwelling individuals and their family care partners has predominantly focused on their level of involvement, decision-making abilities, and responsibilities. They highlighted that the focus is generally on one-off medical or clinical decisions that are often not relevant to everyday decisions or the needs of older people with complex needs (Bunn et al., 2018a) and that shared decision-making appears to have the potential to improve opportunities of people who historically may have been discriminated against (Durand et al., 2014). These reviews usefully bring shared decision-making with people living with dementia into focus, although they largely excluded people living in care homes, who are typically frailer and further along the dementia trajectory than their community dwelling counterparts. The reviews also highlighted that decisions for people living with dementia at home invariably involved a care partner (Bunn et al., 2018a, Durand et al., 2014, Miller et al., 2014, Österholm et al., 2015). However, care partners are often unavailable for many of the day-to-day decisions undertaken in extended care due to time and geographical constraints. As a result, to include people living with dementia in care homes, shared decision-making models need to include long-term relationships with multiple staff and family care partners.

Recommendations for people living with dementia and their care partners to have greater involvement in decisions central to their care (Department of Health, 2012a) are thought to have had limited impact on involvement on everyday decisions such as personal care, diet and medication in care homes (Department of Health, 2015b). Understanding each person’s needs and desires has long been recognised as important to include them in the decisions that shape their health and care (Brooker, 2004, Kitwood and Bredin, 1992) and there is increasing recognition that day-to-day decisions are potentially more significant in everyday quality of life than the more noteworthy issues such as treatment decisions or relocation (see for example; Mariani et al., 2016, Menne and Whitlatch, 2007, Orrell et al., 2008). Therefore, translating what is known about shared decision-making to a care home setting and extending it to involve everyday decisions in ongoing relationships, is seen as an ethical imperative (Coulter and Collins, 2011, Edvardsson et al., 2014a, Edvardsson et al., 2008).

Advance care planning for people living with dementia has been omitted from this work as it considers prospective decisions, predominantly about major life and care choices. It does not therefore, correspond with the ‘everyday’ and contemporaneous nature of how individuals continue to make and share everyday decisions explored here. There is also extensive work acknowledging the need to involve people in decision-making about advance care planning (see for example; Ampe et al., 2017, Elliott et al., 2009, Goodman et al., 2013, Harrison-Dening et al., 2011, Harrison-Dening et al., 2017, Mathie et al., 2012a).

The Mental Capacity Act (2005)

Legislative changes have strengthened the rights and experiences of people living with dementia to participate in decisions about their life and care (United Nations, 2006; Department of Constitutional Affairs, 2005). In England and Wales, the MCA (2005) provides a legislative framework to protect and empower people. Mental capacity is a legal, ethical and philosophical issue that has been much debated in dementia care, primarily with regards to precedent autonomy. The ethical dilemma of whether to respect peoples' last known capacitated wishes over current and developing expressed needs and requests (Dresser, 1995, Dworkin, 1993, Jaworska, 1999) is an ongoing struggle for staff and family care partners. This debate has influenced how decision-making in dementia care is understood and characterised by professionals, care partners and the individuals themselves. There are now multiple sources of evidence which indicate that people living with dementia can reliably report on their priorities and preferences for care, even in moderate to severe dementia (Boyle, 2014, Feinberg and Whitlatch, 2002, Goodman et al., 2013, Whitlatch et al., 2005) and more attention could, and should, be paid to their everyday wishes to inform care planning (Goodman et al., 2013).

In the legal context, mental capacity is dependent on an individual's ability to; understand information relevant to a decision, retain the relevant information, weigh up the information and communicate the decision (Department for Constitutional Affairs, 2005). The first three principles of the MCA align directly with the ethos of shared decision-making, in that; capacity is presumed unless there is sufficient evidence to the contrary, involvement is maximised, and unwise decisions are accepted if the person is considered to have capacity. However, despite an increased awareness of legislation in assessing and addressing the day-to-day needs for individuals living with dementia in extended care (Manthorpe et al., 2011), its interpretation beyond decisions about significant events such as advance care planning, is not well documented (Taghizadeh Larsson and Österholm, 2014).

The key principles of the MCA (2005) are to ensure that an individual's needs are respected and met appropriately, whilst ensuring that the legal process is followed. Evidence suggests however, that some settings rely on staff and family care partners to make decisions for people living with dementia, thereby reducing their decisional autonomy (Boyle, 2008, Manthorpe and Samsi, 2013, Miller et al., 2014). However, non-participation in decision-making can also result from self-protection relating to anxiety about, and reluctance to accept, their diminishing executive abilities (see e.g. Goodman et al., 2013, Mathie et al., 2012, Miller et al., 2014).

Person-Centred Care

Person-centred care is underpinned by the recognition of the person as an individual who is capable of experiencing life and relationships, despite the progressive nature of their 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 sharing decision making" (Edvardsson et al., 2008 p.363).*

Person-centred care is considered to be an ethical and legal requirement throughout the Western world (Edvardsson et al., 2010, Hutchison et al., 2011, Mccormack and Mccance, 2016, Stiggelbout et al., 2012) due to its underpinning principles of respect, self-determination and mutual understanding (Edvardsson et al., 2014b, Mccormack and Mccance, 2016).

Relationship centred care has been proposed as a way of focusing on the value of interdependence in caring for older people in long term care, regardless of the social relationship between the individuals and/or organisations involved (Baldwin and Group;, 2008, Brown-Wilson, 2009, Nolan et al., 2004). The 'Senses Framework' (Nolan et al., 2006, Ryan et al., 2008) was developed to capture the subtleties of caring relationships and represent the intra and inter personal aspects of giving and receiving care from the perspectives of all involved. 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.

Research based interventions have been successful in supporting care staff to implement person-centred and relationship-centred care in a variety of settings (see for example; Dewar and Macbride, 2017, Dewar and Nolan, 2013, Mccormack and Mccance, 2016, Nolan et al., 2006, Nolan et al., 2004). Both approaches aim to enable care staff to develop therapeutic relationships of mutual trust with the people in their settings to promote compassionate and dignified care.

Edvardsson and colleagues (2008) considered the diverse range of concepts and theories associated with dementia care and clustered the Senses Framework in with approaches “synonymous with person-centred care for people with severe AD” [Alzheimer’s Disease] (Edvardsson et al., 2008 p.363). Whilst this misses the relational focus, it does recognise that evidence is consistent in identifying relationships as being a central underlying aspect of positive care experiences (Brown-Wilson, 2009, Dewar and Nolan, 2013, Edvardsson et al., 2008, Mccance et al., 2011, Mccormack, 2004, Nolan et al., 2006, Nolan et al., 2004, Ryan et al., 2008). The Person-Centred Practice Framework (McCormack & McCance 2017) (Figure 2) suggests that shared decision-making, power sharing and effective relationships are essential aspects of any care environment that practices person-centred care. As such it acknowledges the importance of relationships within the care experience and many of the core components of the two approaches align.

Person-centred care has been selected as the theoretical framework of choice for this thesis as it is increasingly accepted as a philosophical underpinning of health and care systems globally (World Health Organization, 2015) and is embedded in UK health and care policy and regulations (MCA, 2005; DH, 2010; Care Act, 2014, CQC, 2014). In addition, a fundamental premise of person-centred care is that knowledge of an individual’s priorities, interests, abilities and character should help to inform shared decision-making about their life and care (Edvardsson et al., 2008, Mccance et al., 2011, Mccormack and Mccance, 2016) which directly aligns with the purpose and ethos of this study.

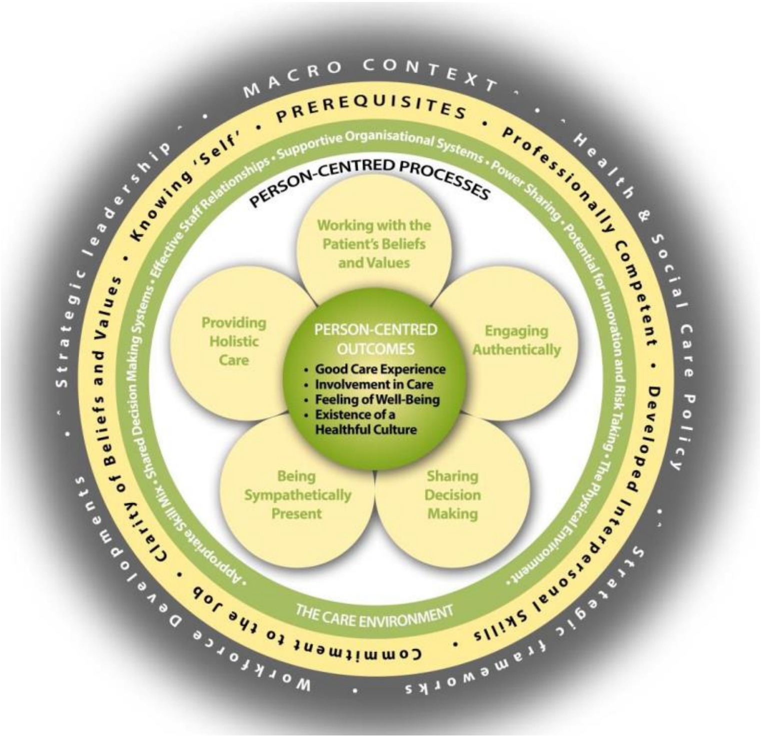

Figure 2: Person-Centred Practice Framework (McCormack & McCance 2017)

Thesis structure

This dissertation is formed of six chapters. The content of each chapter is outlined below to offer the reader an overview of the flow of the dissertation.

Chapter 1 – Introduction

Chapter one presents the motivation for this research and the aims and objectives of the study along with a graphic representation of the study design. It introduces the concept of shared everyday decision-making as an element of person-centred care in the context of the MCA and its use in care homes for people living with dementia and communication difficulties.

Chapter 2 – Systematic Review

The systematic review (Phase 1) is presented in its entirety, including methods and results. This review of the international literature explored interdisciplinary perspectives on how shared everyday decision-making has been characterised, measured, facilitated and implemented for people living with a cognitive impairment in extended care settings over the past two decades. The findings of the review were used to inform the design and conduct of Phase 2 of the study and were published with a view to informing policy and practice (Daly et al., 2018) (see Appendix 1). The review highlighted that people living with cognitive impairment value opportunities to be involved in everyday decision-making about their care. However, there was a lack of clarity about how shared decision-making was understood and enacted in everyday care in care homes.

Chapter 3 – Methods

The research questions for Phase 2 of the study are articulated along with the methodology and ethical challenges associated with including people living with more advanced dementia in research. Appreciative Inquiry (AI) is presented, critically appraised and justified as the methodology of choice to better understand and promote shared everyday decision-making in care homes. The selection and recruitment of the care homes and the participants are rationalised and the modification and application of the AI 4D cycle is defended. Data analysis is described, and the importance of pubic and patient involvement is examined.

Chapter 4 – Discovery Stage Findings

The findings of the discovery stage of the AI are presented as the basis for the application of the remaining stages of the 4D cycle. The study settings and population are described, along with the common everyday decisions that were found to be made by and with people living with dementia and communication difficulties. The spectrum of decision-making and the six factors identified as enabling shared everyday decision-making in the care homes are also reported.

Chapter 5 – Appreciative Inquiry Implementation Stages

Participants stories and ideas were tracked through the dream, design and destiny stages of the 4D cycle along with reasons why participants progressed or abandoned ideas. Five of the original 17 ‘dream’ ideas were implemented to a greater or lesser extent across the two care homes. The ideas implemented were an information board, plating multiple food choices, a post box, a residents’ meeting and 1:1 time with activity staff. Ideas grounded in participant stories, assimilated to the needs of the home and with strong advocates were most likely to be implemented. Participants understanding of shared decision-making was identified as important to the inception, progress and implementation of ideas.

Chapter 6 – Discussion

The findings of the systematic review (Phase 1) and the AI (Phase 2) are brought together and discussed. How people living with dementia and their staff and family care partners understand and employ shared everyday decision-making through a range of enabling factors is discussed in the context of wider shared decision-making theory, decisional capacity and the constraints associated with communal living. The chapter includes a reflection on my role as a researcher/practitioner, the contribution of this thesis to knowledge, strengths and limitations of the study and implications for policy, practice and research. The thesis concludes that people living with dementia and communication difficulties commonly make and share a breadth of everyday decisions with support from their staff and family care partners. Appreciative Inquiry is acceptable to people living with dementia and their care partners. A modified 4D cycle can be effectively employed to implement small changes in the practice and organisational culture of care homes.

Chapter summary

This chapter has provided the contextual background and motivation for the study. The two Phases of the thesis have been outlined along with the aims and objectives and where this study sits in relationship to shared decision-making as it is more traditionally understood, the MCA and person-centred care as recognised frameworks of practice. The content and structure of the thesis has also been outlined.

Chapter 2 - Systematic Literature Review

Introduction

This chapter presents Phase 1 of the study; a systematic review (Daly et al., 2018) (Appendix 1) designed to identify, appraise and analyse existing cross-discipline primary research exploring shared decision-making with cognitively impaired adults in (or transferrable to) an extended care setting. The review approach and methods are described 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 the constructs and frameworks used to assess, measure and understand shared decision-making in the contexts of health and social care. The published review findings provided a comprehensive contemporary synthesis of the international evidence in relation to the current understanding of shared decision-making policy and practice for people living with a cognitive impairment in extended care settings (Daly et al., 2018) (Appendix 1).

The review was conducted drawing on the methods outlined in the Cochrane Handbook of Systematic Reviews of Interventions (Higgins and Green, 2008a). The review protocol (Daly et al., 2016a) (Appendix 2) was designed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and checklist (Moher et al., 2015). To reduce review duplication and promote transparency and replicability the protocol was registered with PROSPERO - international prospective register of systematic reviews (registration number CRD42016035919).

Methods

Aim

The review aimed to understand how everyday decisions are negotiated between people living with a cognitive impairment and their staff and family care partners in extended care settings, to apply transferrable learning to people living with dementia in care homes.

Review Objectives

- Explore how shared decision making is understood and/or characterised for people living with dementia and their (staff and family) carers
- Explore the role of (staff and family) carers of people living with dementia in shared decision-making care dyads
- Analyse identified risks and benefits associated with shared decision making for people with cognitive impairment
- Ascertain empirical evidence for the effectiveness of available shared decision-making resources (such as constructs and frameworks) for people living with dementia
- Seek to understand the barriers and facilitators to effective shared decision making for people living with dementia and their (staff and family) carers
- Explore the extent to which shared decision making has been researched in extended care settings
- Identify implications for shared decision making in dementia care practice, policy and future research

Inclusion Criteria

Inclusion criteria are presented in *Table 1* below (also see Appendix 2). A 20-year time limit was applied to reflect the rapidly changing literature on how people living with dementia are involved in their care since the seminal works of Tom Kitwood (Kitwood, 1997b, Kitwood, 1997a, Kitwood, 1997c, Kitwood and Bredin, 1992, Kitwood and Bredin, 1997). The focus of the review was on people with dementia but studies relating to adults with other types of cognitive impairment were included to improve the potential for transferable learning.

Exclusion Criteria

Studies concentrating on advance decisions or advance care planning were excluded. The focus of this review was on current everyday decisions being shared between the cognitively impaired person and their staff or family care partner. There is significant literature on advance care planning and proxy decision-making for people living with dementia, which acknowledges the need to involve people in decision-making. This literature does not however discuss how this can be applied to everyday decision-making about care (see for example, Ampe et al., 2016, Elliott et al., 2009, Goodman et al., 2013, Mitchell, 2015).

Studies that focused on decisions made primarily by health or social care staff and, or family care partners for people, and those that did not directly include the person living with a cognitive impairment were excluded.

Table 1: Inclusion Criteria (Daly et al., 2018)

Inclusion Criteria	
Publication Language	English
Publication Dates	January 1996 – January 2018
Target Population	Adults aged over 18 years, with any type of cognitive impairment including (but not limited to); dementia, learning disabilities, Parkinson’s and Huntington’s disease
Study Setting	Community living at home or extended care settings including; supported living, or residential care. Studies must be considered transferable to people living with a cognitive impairment in an extended care setting (for example, the person living with a cognitive impairment must be in receipt of care in addition to that provided by a family care partner and the resource should be suitable for implementation in extended care settings.
Study Types	All quantitative and qualitative research designs.
Intervention Types	Any intervention designed to understand, influence, measure or facilitate shared everyday decision-making that included the person living with a cognitive impairment as an active participant in decisions about their care.
Primary Outcomes	Any everyday shared decision-making outcome relating to involvement in care planning, where care was congruent with the persons expressed choice, quality of life or wellbeing, and behavioural changes (e.g. reduction in distress)
Additional Outcomes	Family care partner and/or health or care professional satisfaction, and any documented adverse effects (e.g. falls, weight loss, adverse outcomes related to medication management).

Search Strategy

The search strategy was applied to cross-disciplinary electronic databases associated with cognitive impairment and dementia care. Electronic databases searched, an example of the full search query for PubMed, and the search terms used in Google Scholar are shown in *Table 2*.

Medical Subject Heading (MeSH) search terms were combined with Boolean operators AND, OR and NOT for an inclusive search strategy for PuBMED and other electronic databases which recognise 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 subcategories 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 performed on Google Scholar, and PubMed to detect any additional relevant studies. Searches were undertaken in June 2016, updated in January 2018 prior to publication, and revisited in May 2019. Lateral searches were completed in November 2016. Alerts were created using the search terms on Google Scholar, National Centre for Biotechnology Information (NCBI) and JAMA Network Open to provide a constant awareness of relevant contemporaneous literature.

Amendments

To promote transparency and replicability and to reduce bias, amendments to the protocol were described, dated and rationalised on the PROSPERO systematic review register (https://www.crd.york.ac.uk/prospero/) registration number CRD42016035919 and in the published review (Daly et al., 2018).

Table 2: Databases Searched and Search Terms Used (Daly et al., 2018)

Search Strategy	
Electronic databases	CINAHL Plus, PubMed, the Cochrane Library, NICE Evidence, OpenGrey, Autism Data, Google Scholar, Scopus and MedicinesComplete
MeSH search terms (with subheadings included)	Cognition Disorders searched (((("dementia"[MeSH Terms] OR "dementia"[All Fields]) OR ("cognitive dysfunction"[MeSH Terms] OR ("cognitive"[All Fields] AND "dysfunction"[All Fields]) OR ("cognitive"[All Fields] AND "impairment"[All Fields]) OR "cognitive impairment"[All Fields])) OR ("learning disorders"[MeSH Terms] OR ("learning"[All Fields] AND "disorders"[All Fields]) OR ("learning"[All Fields] AND "disability"[All Fields]) OR "learning disability"[All Fields])) OR ("autistic disorder"[MeSH Terms] OR ("autistic"[All Fields] AND "disorder"[All Fields]) OR "autistic disorder"[All Fields] OR "autism"[All Fields])) OR ("stroke"[MeSH Terms] OR "stroke"[All Fields])) OR ("brain injuries"[MeSH Terms] OR ("brain"[All Fields] AND "injuries"[All Fields]) OR "brain injuries"[All Fields] OR ("brain"[All Fields] AND "injury"[All Fields]) OR "brain injury"[All Fields])) OR ("neurocognitive disorders"[MeSH Terms] OR ("neurocognitive"[All Fields] AND "disorders"[All Fields])) OR ("alzheimer disease"[MeSH Terms] OR ("alzheimer"[All Fields] AND "disease"[All Fields]) AND Shared Decision-making ((((((shared[All Fields] AND ("Decision (Wash D C)"[Journal] OR "decision"[All Fields])) OR ("decision-making"[MeSH Terms] OR ("decision"[All Fields] AND "making"[All Fields]) OR "decision-making"[All Fields])) OR ("community participation"[MeSH Terms] OR ("community"[All Fields] AND "participation"[All Fields]) OR "community participation"[All Fields] OR ("consumer"[All Fields] AND "participation"[All Fields]) OR "consumer participation"[All Fields])) OR ("patient participation"[MeSH Terms] OR ("patient"[All Fields] AND "participation"[All Fields]) OR "patient participation"[All Fields])) OR "decision"[All Fields]) AND support[All Fields])) OR (care[All Fields] AND dyad[All Fields])) OR "patient education as topic"[MeSH Terms] OR "patient education"[All Fields]))) NOT (((advance[All Fields] AND ("Decision"[All Fields])) OR ("advance directives"[MeSH Terms] OR ("advance"[All Fields] AND "directives"[All Fields]) OR (advance[All Fields] AND care[All Fields] AND plan[All Fields])))) OR (((((("Dementia"[Mesh] OR "Neurocognitive Disorders"[Mesh]) OR "Brain Injuries"[Mesh]) OR "Stroke"[Mesh]) OR "Learning Disorders"[Mesh]) OR "Autistic Disorder"[Mesh]) AND ((((("Decision-making"[Mesh] OR "Decision Support Techniques"[Mesh]) AND "Patient Participation"[Mesh]) NOT Advance Directives("Advance Directives"[Mesh] OR "Advance Care Planning"[Mesh]))) NOT Paediatrics ("child"[MeSH Terms] OR "child"[All Fields])) NOT ("Child"[Mesh] OR "Disabled Children"[Mesh])
Alternate free text search terms	(Cogniti*, Disorder*, Dementia*, Alzheimer*, Neurocogniti* Dis*, Brain Injur*, Autis*, Learning Dis*, Stroke) AND (Shared Decision-making, Deci* Mak*, Patient Participat*, Consumer Participat*, Cooperat*, Decision Support) NOT (Paed* Child*) NOT (Advance Directives, Advance* care planning, Advance* deci*)
Google Scholar	The search and screening strategy for Google Scholar was agreed by all 3 authors. Free text search terms mirrored other databases. Results were filtered by relevance. The first 20 pages of results, title and abstract, were screened (20 results per page).

Study Screening and Data Extraction

Electronic search results were downloaded into EndNote bibliographic software and duplicates were removed. Titles and abstracts were screened against the inclusion criteria that decision-making must involve the person living with a cognitive impairment and relate to everyday care. Excluded studies focused on: major decisions such as admission to residential care (e.g. Caron et al., 2006, Chang and Schneider, 2010, Forbes et al., 2012), physician/ patient decisions centring on medical treatment options (e.g. Chrisp et al., 2013, Karel et al., 2010) and those that only referred to proxy decision makers (e.g. Dunn et al., 2013, Livingston et al., 2010). Other excluded studies related to ethical and legal capacity issues (e.g. Black et al., 2008, Lui, 2012, Mäki-Petäjä-Leinonen and Juva, 2015), decision-making strategies in older adults without cognitive impairment (Mata, 2007), and exploring only carers perspectives (Fetherstonhaugh et al., 2014, Wolfs et al., 2012).

Full-text manuscripts of all potentially relevant citations were obtained and screened. Data were extracted using a form designed to collect information addressing the review objectives, including information about the study design, participants and outcomes. The process for filtering the results can be seen in Figure 3 PRISMA diagram (Moher et al., 2015).

Quality Assessment

The QualSyst Framework (Kmet et al., 2004) was used to assess the quality of included studies. This validated framework (Kmet et al., 2004, Laidsaar-Powell et al., 2013, Légaré et al., 2008) provides comprehensive instructions, and a system for scoring the quality of quantitative and qualitative studies. However, it is recognised that the efficacy of the QualSyst framework may be questioned due to the dual-purpose design (Kmet L, 2004). Scores are presented as a percentage (with a greater percentage representing higher quality)(Kmet et al., 2004).

Ethical approval reporting has been highlighted as an important component of study quality (Hannes, 2011, Noyes et al., 2015). However, this framework does not include assessment of ethical clearance, so ethics were checked in addition to the QualSyst score.

Analysis

Owing to heterogeneity, and low numbers of quantitative studies meta-analysis was not possible. Results of qualitative and quantitative studies are therefore reported in a 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. This method of synthesising qualitative research enabled in depth exploration of themes and areas of interest (Braun and Clarke, 2006, Clarke and Braun, 2014).

Results

Twenty publications were included after the search was updated in May 2019 (Bailey et al., 2011, Boyle, 2014, Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Ferm et al., 2010, Fetherstonhaugh et al., 2013, Godwin, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Kjellberg, 2002, Menne and Whitlatch, 2007, Menne, 2008, Milte et al., 2015, Murphy and Oliver, 2013, Samsi and Manthorpe, 2013, Sinclair et al., 2018, Smebye et al., 2012, Span, 2016, Tyrrell et al., 2006, Whitlatch et al., 2005) relating to 19 unique studies. Four of the papers were linked in that the participants were drawn from the same sample pool (Feinberg and Whitlatch, 2002, Menne and Whitlatch, 2007, Menne, 2008, Whitlatch et al., 2005). However, as the studies addressed different questions, they are all included.

Study Quality

Study quality ranged from 65-100 per cent. A high risk of bias was noted in some studies. For example, one study designed the measure used to assess the impact of their own intervention (Ferm et al., 2010). Eight studies did not provide a clear ethics statement (Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Ferm et al., 2010, Fetherstonhaugh et al., 2013, Menne and Whitlatch, 2007, Murphy and Oliver, 2013, Tyrrell et al., 2006, Whitlatch et al., 2005), including two studies that scored 100 per cent on QualSyst quality assessment tool (Menne, 2008, Whitlatch et al., 2005).

The quantitative studies consistently scored highly (79 per cent or above). One of the studies described randomly allocating the intervention (Bailey et al., 2011) but no studies randomly allocated or blinded investigators or subjects. One study (Bailey et al., 2011) reported a low sample size (n=24) which suggests that the findings may not be generalisable.

All the qualitative studies achieved a maximum score in at least six of the twelve areas assessed. Qualitative studies scored between 65 per cent and 95 per cent. One study did not report a link to a wider theoretical framework (Clarke and Davey, 2004) and six further studies were unclear about links to theoretical frameworks (Ferm et al., 2010, Fetherstonhaugh et al., 2013, Horton-Deutsch et al., 2007, Kjellberg, 2002, Smebye et al., 2012, Span, 2016). Two papers did not clearly articulate sampling strategies (Fetherstonhaugh et al., 2013, Murphy and Oliver, 2013). Finally, three studies did not describe a verification procedure to establish credibility (Godwin, 2014, Kjellberg, 2002, Murphy and Oliver, 2013).

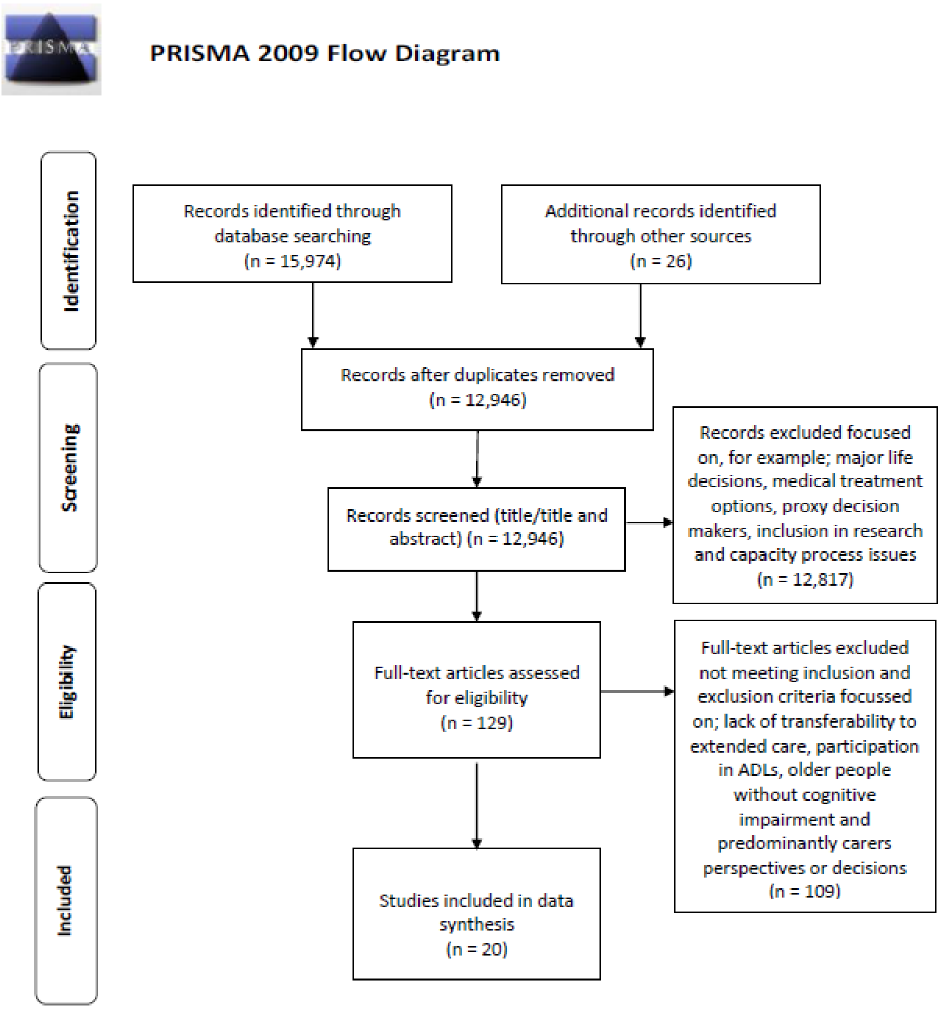

Figure 3: PRISMA Flow Chart (Moher et al., 2015)

Characteristics of Included Studies and Participants

All included studies were published between 2002 and 2018, with the majority (n=14) of studies being published in the last 10 years. This suggests an increase awareness and interest in shared decision-making for people living with a cognitive impairment in line with changes in national and international legislation. For example, all five UK studies were published since the full implementation of the Mental Capacity Act (Department of Constitutional Affairs, 2005).

Most papers (n=16) focused on people living with dementia (Boyle, 2014, Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Godwin, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Menne and Whitlatch, 2007, Menne, 2008, Murphy and Oliver, 2013, Samsi and Manthorpe, 2013, Sinclair et al., 2018, Smebye et al., 2012, Span, 2016, Tyrrell et al., 2006, Whitlatch et al., 2005); thirteen studies looked at shared-decision making interactions in 'care dyads' (with a care partner) or 'triads' (with a family care partner and a health or care worker). Two papers concentrated on people with a learning disability (Bailey et al., 2011, Kjellberg, 2002), one on people with Huntington's disease (Ferm et al., 2010) , and one involves some people with cognitive impairment (Milte et al., 2015). Eight studies include some participants living in extended care settings (Clarke and Davey, 2004, Godwin, 2014, Hirschman et al., 2005, Kjellberg, 2002, Milte et al., 2015, Sinclair et al., 2018, Smebye et al., 2012, Span, 2016, Tyrrell et al., 2006). The majority (n=12) relate solely to people living at home. Of the 20 studies included, only two specified *shared decision-making in extended care settings* as their explicit focus (Clarke and Davey, 2004, Godwin, 2014).

Most studies (n=16) used interviews and/or observations as data collection methods. Three of the linked studies compared the views of people living with a cognitive impairment and their care partners (Feinberg and Whitlatch, 2002, Menne, 2008, Whitlatch et al., 2005) through structured interviews. One study, observed family meetings (Milte et al., 2015) and three studies used ethnographic observations of people living with dementia within a care dyad or triad (Boyle, 2014, Clarke and Davey, 2004, Smebye et al., 2012). Person centred care was the primary theoretical framework identified, although that was only in four studies (Boyle, 2014, Godwin, 2014, Murphy and Oliver, 2013, Span, 2016).

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 shared decision-making participation or involvement with people living with a cognitive impairment in terms of; understanding, how it is measured, facilitated and/or inhibited and benefits for participants.

Understanding ‘Shared Decision-Making’ for People Living with Cognitive Impairment

There was no common understanding of what shared decision-making entails, and how it can be operationalised for people living with a cognitive impairment in the included studies. Only one study offered a definition of shared decision-making, based on an approach that involves patients in making medical decisions with their clinician, taken from Elwyn and colleagues (2010). This was influenced by the type and complexity of the decision and the perspectives of care partners as well as the person living with cognitive impairment. This clinical model did not appear to be transferrable to all settings or in all contexts. For example, decisions for people living in residential care were rarely clinical and sometimes relied on incremental decisions shared with multiple care staff.

Through a phenomenological approach, Fetherstonhaugh et al. (2013) identified three ways that people living with dementia understand shared decision-making. These were; subtle support versus taking over; hanging on versus letting go; and being central versus being marginalised or excluded. Participants living with dementia were clear that they wanted to remain involved in and central to decision-making processes, with almost imperceptible support from their care partners. One participant described their response to being marginalised;

> *“…if someone came in and started telling me how I should run things or do things, I think I would certainly retaliate and not conform to anything they would want to do.”* (Fetherstonhaugh et al., 2013 p.147).

Sinclair and colleagues (2018) also identified three ways that couples understand shared decision-making in dementia care. Dyadic interviews suggested the overarching themes of; knowing and being known, maintaining and re-defining ‘couplehood’, and relational decision-making. Relational factors were situated in communication and commitment developed over extended periods of time, and decision-making was thought to require adjustments as the effects of dementia became more pronounced.

A recurrent theme from the included studies was that for many people living with dementia, the involvement or ‘sharing’ in the decision-making process, was as important, (if not more important,) than making the decision itself (Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Horton-Deutsch et al., 2007, Tyrrell et al., 2006). Despite this, Samsi and Manthorpe (2013) identified multiple examples of what they termed ‘substituted decision-making’. For example, a family care partner told them;

> *“Oh, I don't ask her what she wants anymore. I know what she'll say anyway - ‘anything you like, you decide’, so I just do what's best for us both.”* (Samsi and Manthorpe, 2013 p.958).

Participation in decision-making

The extent to which a person living with dementia can participate in decision-making was a focus of many of the included studies. Participation in decision-making was sub-categorised into; the degree or level of participation, ability to participate and desire to participate.

Levels of participation

Six studies addressed different levels of participation (Horton-Deutsch et al., 2007, Kjellberg, 2002, Samsi and Manthorpe, 2013, Sinclair et al., 2018, Smebye et al., 2012, Tyrrell et al., 2006). Smebye (2012) used and extended Thompson’s five-point taxonomy (see Table 3: Taxonomy of Decision-Making (Thompson, 2007)) to include people living with dementia. Thompson’s taxonomy of patient participation in health care consultations, was designed to understand the involvement of people who were cognitively able and ranged from the entirely passive ‘non-involvement’, through co-operative ‘shared decision-making’, to independent or ‘autonomous decision-making’ (Thompson, 2007). Smebye (2012) identified two additional elements through observations and interviews with care triads; pseudo-autonomous (assumptions about the decision a person might make), and delegated (the person living with dementia expressly delegates their decision-making). The levels of participation in this extended taxonomy were reflected in all five studies exploring the extent of decision-making participation, although the terminology differed between studies.

Table 3: Taxonomy of Decision-Making (Thompson, 2007)

Level	Patient determined	Co-determined	Professional determined
4	Autonomous		Informed decision-making
3		Shared decision-making	Consultation
2	Information giving		Professional as agent
1	Information seeking		Information giving
0	Non-involvement		Exclusion

Shared-decision-making was considered the most common decision-making pattern by people living with a cognitive impairment. Horton-Deutsch and colleagues (2007) explored self-reported participation in decision-making for 20 people living with dementia and their family care partners', using semi-structured interviews and a five-point decision making scale centred on a treatment vignette. The scale ranged from (1) made decisions alone in the past with little input from others and continue to do so, to (5) discussed decisions with spouse in the past and continues to do so. Participants reported that although their decision-making had changed over time from, largely independent to interdependent decision-making, the majority (75 per cent) of participants described maintaining a level of shared decision-making throughout their decision-making history (Horton-Deutsch et al., 2007). Similarly, in a group of 23 people living with varying levels of learning disability, 70 per cent rarely considered themselves entirely independent in their decision-making and relied on sharing decision in some or all areas of their lives (Kjellberg, 2002).

Samsi and Manthorpe (2013) and Sinclair and colleagues (2018) acknowledged the importance of autonomy and assistance in decision-making, whilst recognising that most dyads adopted a decision-specific approach that was context dependent and was influenced by; individual, relational, decisional and external factors. Individual factors included personal preference and willingness to accept help, Relational factors included trust and familiarity and decisional factors included time, risk and importance of decision.

Ability to participate

Seven studies (Bailey et al., 2011, Boyle, 2008, Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Hirschman et al., 2005, Menne, 2008, Whitlatch et al., 2005) explored individuals’ ability to participate, or share, in decision-making, often in the context of facilitators or barriers (e.g. Clarke and Davey, 2004). Studies measuring decision-making participation compared the responses of the person living with a cognitive impairment with those of their care partners. Hirschman (2005) and Whitlatch (2005) noted incongruence between the responses of care partners and people living with dementia; with family care partners consistently perceiving people to be less involved than they perceived themselves to be.

Five papers described and/or evaluated tools that measured aspects of decision-making participation from the perspective of the person living with a cognitive impairment (Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Godwin, 2014, Horton-Deutsch et al., 2007, Tyrrell et al., 2006). The linked studies (with a sample ranging from 51-217 care dyads) developed, used and evaluated the Decision Control Inventory (DCI) and the Decision-Making Involvement Scale (DMI) to assess and compare the everyday care choices of the person living with cognitive impairment and their care partner (Feinberg and Whitlatch, 2002, Menne and Whitlatch, 2007, Menne, 2008, Whitlatch et al., 2005). The DMI Scale measures involvement in everyday decisions, such as what food to eat and when to go to bed. It aims to increase participation through improved communication and care planning (Whitlatch et al., 2005). The DCI explores the abilities of people living with dementia to control everyday decision-making preferences. The majority of the findings were about home based care, identifying that family care partners were primarily chosen as substitute decision-makers for people living with dementia, although this appeared to be affected by financial strain on the family (Feinberg and Whitlatch, 2002, Menne and Whitlatch, 2007, Menne, 2008).

Tyrrell et al. (2006) explored decision-making participation through qualitative interviews with 21 care dyads of older people living with dementia and their family care partners. Themes identified were; information received, being listened to, ability to express an opinion, time allowed for reflection, and opportunity to change the decision. People living with dementia discussed feelings of not being given enough time to reflect on their decisions or having opportunities to change their mind. They also reported feeling that their views about care provision were not listened to. Care partners reported higher levels of satisfaction with the quality of the communication and decision-making process than people living with dementia (Tyrrell et al., 2006).

One study explored the *desire* of the person living with dementia to participate in decision-making (Hirschman et al., 2005). The study used a vignette to explore whether 48 people living with dementia would wish to participate in the decision to take a medication to slow the advancement of Alzheimer's disease, and what factors, (including family,) might influence their participation. Ninety-two percent of the participants living with dementia wanted to share in the decision, although only 71 per cent of their family care partners thought they would. Participants living with dementia concentrated on their *involvement* in the decision-making *process*, whilst their care partners focused on people's *capacity* to participate. Paradoxically, the family care partners of the 29 participants living with dementia who were assessed as lacking capacity, said that they would involve their relative in the decision-making process (Hirschman et al., 2005). This raises questions about how people understand and discuss the process, and how easy it is to establish a common understanding of what shared decision-making is and what is involved in the context of dementia care. This question is further explored in Chapter 6 (Discussion).

Facilitators of and barriers to shared decision-making

Care Partners and professionals

Relationships with staff and family care partners were identified as facilitators and/or barriers to shared decision-making (see e.g. Clarke and Davey, 2004, Fetherstonhaugh et al., 2013, Horton-Deutsch et al., 2007, Samsi and Manthorpe, 2013, Sinclair et al., 2018). The impact of relationships between people living with dementia and their care partners on decision-making involvement is well documented (Boyle, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Menne, 2008, Samsi and Manthorpe, 2013). However, only two studies explicitly discussed *who* should share in decision-making process and their roles (Sinclair et al., 2018, Span, 2016). Few studies have focused on shared everyday decision-making relationships in extended care settings with care staff; the majority has been undertaken in care dyads within the home environment (see e.g. Miller et al., 2014, Sinclair et al., 2018, Taghizadeh Larsson and Österholm, 2014).

Clarke and colleagues (2004) studied care home staff characteristics, to identify if they could be facilitators or inhibitors of decision-making involvement for people living with dementia. They associated positive characteristics, including; warmth, encouragement with memory, and routine as shared everyday decision-making facilitators. Routine was also described as a barrier to involvement if it was linked to task orientated care. Other negative characteristics identified were: discouraging independence, depersonalisation and risk adversity. Researchers reported more negative incidents than positive ones and felt that peoples autonomy and dignity was compromised (Clarke and Davey, 2004).

Opportunities for people living with dementia to express choice appeared to diminish as daily care needs increased in extended care settings (Godwin, 2014, Kjellberg, 2002). However, these daily care needs were not necessarily related to cognitive impairment, and they were not always incremental. For example, people with severe learning disabilities whose cognitive abilities were stable, appeared to have fewer decision-making opportunities than their peers with milder cognitive impairment. These reduced opportunities were identified in three studies as related to: social attitudes, lack of available choices and operational systems as barriers to shared everyday decision-making (Kjellberg, 2002, Smebye et al., 2012, Span, 2016). Span (2016), also noted that staff and family care partners tended to recognise more problems than opportunities to involve people living with dementia in decisions about their everyday life and care. Optimum shared everyday decision-making was achieved by care partners; giving and sharing information, offering some support and reinforcing the opinions of the person living with a cognitive impairment (Boyle, 2014, Smebye et al., 2012, Tyrrell et al., 2006). Ultimately, by recognising the person as capable of influencing the decision.

Tools and resources

Tools and/or resources to facilitate shared everyday decision-making for people living with a cognitive impairment were evaluated in four studies (Bailey et al., 2011, Ferm et al., 2010, Murphy and Oliver, 2013, Span, 2016). Two of the studies evaluated Talking Mats (TMs) - a picture-based communication tool, enabling people to indicate their feelings within a specified topic area by placing the most appropriate picture on a board. The studies compared TMs with other structured and unstructured communication methods with five people in the late stages of Huntington’s disease (Ferm et al., 2010), and with usual communication methods with 18 people living with dementia and their family care partners (Murphy and Oliver, 2013). Both studies reported positive outcomes, with improvements in communication satisfaction when using TMs. Although one study, (Murphy and Oliver, 2013) identified that satisfaction was higher for the carers than for the people living with dementia.

Two studies developed and evaluated computerised tools to support shared decision-making (Bailey et al., 2011, Span, 2016). Span and colleagues (2016) co-designed an interactive web based tool with people living with dementia and their care partners, to promote their involvement in decision-making in care networks. Topics such as; social contacts, activities, mobility, safety, finance and future care were included (Span, 2016). Bailey and colleagues (2011) created a computerised visual aid for people living with learning disabilities to present information in a more comparable format to help them share in decision-making. They suggested that creating uniformity throughout the decision process could help people to compare everyday choices and outcomes. Participants with a learning disability who were trained to use the visual aid increased their level of decision-making involvement, although ongoing use of the tool was required to maintain the improvement (Bailey et al., 2011).

Benefits of shared decision-making for people living with a cognitive impairment

Godwin (2014) consulted with residents living with dementia in a care home about the décor. She suggested that this kind of consultation could enhance their self-esteem and contribute to their quality of life because residents appeared to be “surprised and pleased” to be asked (Godwin, 2014 p. 114). Other studies have identified benefits of shared everyday decision-making in people living with a cognitive impairment as; heightened self-esteem, a sense of purpose and feelings of self-worth (Fetherstonhaugh et al., 2013), reduced depressive symptoms and preserved everyday abilities (Menne and Whitlatch, 2007).

Search Updates

The searches were updated in January 2018 and May 2019, with 139 potential new articles returned using the original search terms. Screening of titles and abstracts revealed that 134 did not meet the review criteria. The remaining five papers (Groen-Van De Ven et al., 2017, Mariani et al., 2017, Sinclair et al., 2018, Alzheimer's Society;, 2017, Span et al., 2018) full text were screened. Two papers (Groen-Van

De Ven et al., 2017, Span et al., 2018), were excluded as they were publications from the Span (2016) PhD dissertation and the data was therefore already included in this review. The focus of the Alzheimer’s Society report (2017) was about the impact of living with dementia and not on shared everyday decision-making. The study dedicated to shared decision-making in dementia care in care homes in two European Countries (Mariani et al., 2017) was relevant, however this paper only reported on staff perspectives of their training implementation study, and so did not meet the criteria for this review. One paper met the inclusion criteria and has been integrated into the review (Sinclair et al., 2018)

An intervention study protocol designed to promote person-centred care and thriving in extended care setting was identified (Edvardsson et al., 2017) along with an integrative literature review of everyday decision-making for people living with Alzheimer's Disease (Davis et al., 2017). Despite their relevance, neither publication was included in this review as they did not present primary research outcomes.

Most of the shared everyday decision-making literature located through the *a priori* search terms remained related to decisions made by staff and family care partners about, rather than with, people living with dementia. Although there appears to be a shift in inclusion of, and shared decisions with, people living with a cognitive impairment in treatment and medical decisions, work in care homes and everyday decisions, remains restricted.

Discussion

The results of the systematic review have been used to develop the intervention phase of the study. An overview of what is known about shared everyday decision-making with people living with dementia or another cognitive impairment has helped to locate gaps in the available empirical evidence, namely; how people living with dementia make and share decisions about their everyday life and care in care homes and the decisions that they make and share. A brief summary of the results here is complemented by a more in-depth discussion of this literature in the context of the findings of Phase 2, the AI intervention study.

Available evidence suggests that people living with a cognitive impairment want to be given the opportunity to participate in everyday decision-making about their health and care and that this is underestimated by their staff and family care partners (Horton-Deutsch et al., 2007, Kjellberg, 2002, Samsi and Manthorpe, 2013, Smebye et al., 2012, Tyrrell et al., 2006). How people choose a decision partner, and how they use available resources to *lead* decisions is less clear. Shared decision-making has the potential to have a positive influence on people's self-worth and improve their quality of life (Fetherstonhaugh et al., 2013, Hirschman et al., 2005, Tyrrell et al., 2006), and this finding appears to be consistent regardless of the living environment (Clarke and Davey, 2004, Godwin, 2014). The lack of opportunity to share in everyday decision-making appears to be a significant and consistent barrier (e.g. Clarke and Davey, 2004, Kjellberg, 2002, Milte et al., 2015, Smebye et al., 2012). However, the causes appear to be complex and multifaceted, including; confusion about the definition and implementation of shared everyday decision-making with people living with cognitive impairment, lack of choice opportunities, and a lack of skill in understanding peoples' desire and ability to share in a decision (Milte et al., 2015).

Strengths and Limitations

This review included a systematic and thorough search of the literature relevant to shared everyday decision-making for people living with pre-defined cognitive impairments in a range of extended care settings. As such, it provides a foundation for future related research and practice. However, most of the studies identified were executed in people's own homes, study quality was inconstant and minimal evidence was found to better understand what supports the sharing of everyday decisions between people living with a cognitive impairment and their staff and family care partners in extended care settings.

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, including 'choice', may have identified additional relevant studies that were not identified through the selected terms. A strength is that the review highlighted difficulties in defining what is meant by shared everyday decision-making for people who are cognitively impaired.

The QualSyst tool (Kmet et al., 2004) has the positive aspect of assessing qualitative and quantitative studies, however it does not assess ethical acceptability which is recognised as a limitation.

Chapter Summary

The limited empirical evidence relating to shared everyday decision-making in extended care environments fails to provide a broadly agreed definition of shared everyday decision-making for people living with cognitive impairment in extended care, which leads to confusion about how the process can be embraced and embedded into practice.

People living with cognitive impairment appreciate opportunities to be involved in the process of everyday decision-making about their life and care. However, their desire to participate is regularly underestimated and misunderstood by staff and family care partners, which has implications for the significance of interdependent relationships between people living with dementia and their care staff develops as difficulties associated with dementia, activities of daily living and communication, increase.

From the literature, there was a lack of understanding of the decisions that people living with dementia make and share every day in care homes. Tools and resources to support shared decision-making largely fail to empower the person living with a cognitive impairment to take control of the decision and they do not appear to have been widely evaluated in extended care settings. A gap was also identified in understanding how communicative abilities affect shared everyday decision-making between a person living with dementia and their staff and family care partners, in the context of communal living.

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 shared decision-making tools or resources and to implement and further evaluate them with people living with dementia in care homes. However, no financially viable sources or standard methodology to understand and facilitate shared everyday decision-making in care homes was identified. As Appreciative Inquiry has successfully been used in other care home studies (Amador et al., 2016, Goodman et al., 2013, Yoon et al., 2011) it was selected as an appropriate methodology for Phase 2 of the study.

CHAPTER 3 - METHODS

Introduction

This chapter provides a rationale for the decisions and actions I took in developing the study design, methodology, data collection methods and analysis. The methods for Phase 2 of the study (Figure 4), are presented here. The Phase 1 systematic review led to refinement of the research questions and the choice of Appreciative Inquiry (AI) as a methodology. The research questions and methodology are discussed in the context of current care home research and practice. Each element of Phase 2 of the study are then described in detail; demonstrating why the methods were selected to answer the research questions, and how they were adapted to meet individual and organisational needs. Specifics of the ethics process are also presented due to the complexity of the consent processes for participants living with dementia.

Research Questions

The research questions for Phase 2 were developed from a combination of clinical experience working in, and with, residential and nursing care homes, and the results of the systematic review (Daly et al., 2018).

The research questions were:

- What are the key everyday decisions that people living with dementia and communication difficulties make and share with their staff and family care partners in care homes?
- How are opportunities for shared decision-making understood and facilitated, by people living with dementia and communication difficulties, and their staff and family care partners in care homes?
- Could AI be used to capture participants stories and experiences to facilitate and share positive shared everyday decision-making in care homes?

Phase 2 study design

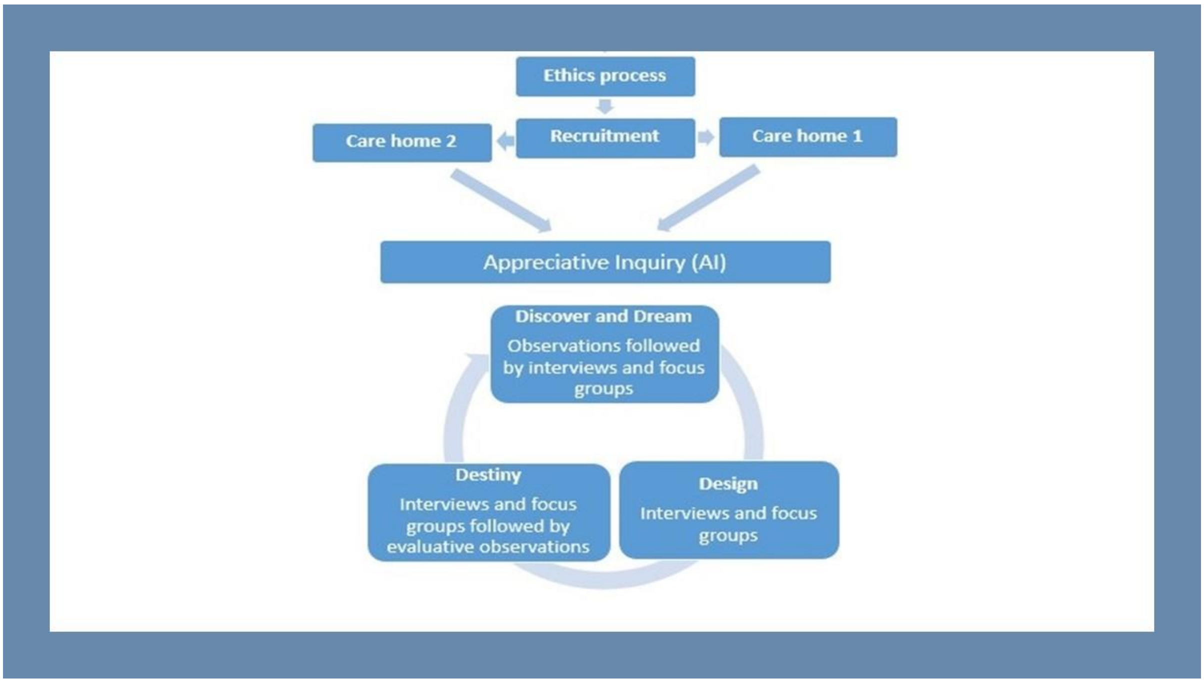

Figure 4: Phase 2 Study Design Diagram

Shared decision-making

For the purposes of phase two of this study, the working definition of shared decision-making drew on the work of Stiggelbout et al. (2012) and Coulter and Collins (2011). Shared decision-making in dementia care is a partnership which enables people to make:

> *'…treatment, management or support decisions based on best available…evidence and the patient's own values and preferences. It involves eliciting the patient's ideas, concerns and expectations and the provision of evidence-based information about options, outcomes and uncertainties.'* (Daly et al., 2016b p. 2)

Methodological Approach – Appreciative Inquiry

Appreciative inquiry is a philosophy and methodology for studying and effecting change in social systems through the identification of what people in that system perceive to be good practice. AI is underpinned by five principles (Cooperrider and Whitney, 2001)(Table 4). It invites participants to share their own thoughts, stories and experiences to create new and deeper connections. This in turn enhances their self-esteem and self-expression and inspires participants to generate positive new ideas for self-determined and collaborative change (Cooperrider and Srivastva, 1987, Whitney, 2010). Through this process AI redirects the focus from a traditional problem-based approach to a progressive and developmental approach based on future possibilities (Bushe, 2011, Carter, 2006, Cooperrider and Whitney, 2005, Cooperrider et al., 2003a).

This study aimed to use AI as a method of identifying what people living with dementia and communication difficulties can achieve with their staff and family care partners in care homes in relation to shared decision-making. It was the basis for exploring how shared decision-making enhances the lives of people living with dementia and the effects of communication difficulties on the shared decision-making process in care homes. The AI approach complemented the core assumptions of the shared decision-making process and the ethical imperative to involve everyone equally, and to mitigate inherent power inequalities that may arise between staff and residents.

Table 4: 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 shape the way they behave and move forwards.
The positive principle	By asking positive questions people are more deeply engaged and envision more boldly for a longer time; creating momentum for change, with hope and inspiration.

The inclusivity of AI draws on the assumptions of participatory action research (Nolan, 2007) and recognises the equal value of all stakeholders as participants in the research process (Backhouse et al., 2016, Heron and Reason, 1997). Appreciative Inquiry encourages and enables participants to be involved in the entire research process (Pollard and Evans, 2013) and gains multiple perspectives and interpretations. PAR challenges assumptions that knowledge is objective or impartial (Nolan, 2007) because the conceptualisation and construction of knowledge is partially ‘owned’ by the participants. Shared ownership of the AI process is thought to be crucial to the implementation and sustainability of any practice developments that affect the participants and their environment (Clouder and King, 2015, Cooperrider et al., 2008, Nolan, 2007, Senior and Fleming, 2006). In promoting the active involvement of all participants, the AI reflects a shared-decision-making process between the people living with dementia and their staff and family care partners.

Appreciative Inquiry is an approach that has been widely used to co-create effective, sustainable outcomes in a variety of settings including health and social care. It has been successfully employed in working with, and empowering older adults to review and refine their own care in hospital, community and extended care settings (Dewar and Nolan, 2013, Goodman et al., 2015, Iliffe et al., 2015, Mccormack, 2004, Meyer and Owen, 2008, Nolan et al., 2004, Seebohm et al., 2010). The flexibility of the AI process means that it can be tailored to individual participants’, and organisations’ needs, and grounded in their experience. Participant enthusiasm, engagement and commitment have been identified as important to the success of AI in a range of healthcare settings (Trajkovski et al., 2013).

Bushe (2011) proposed that the ‘intuitive appeal’ of AI with its focus on what works, and the assets of an organisation means that there was limited critique of AI, with few authors choosing to fully engage with its theoretical sources and assumptions. However, more recently, systematic reviews and meta-analyses of AI as a methodology in health, social care and education have provided a more comprehensive overview, and critique (Bushe, 2011, Clouder and King, 2015, Trajkovski et al., 2013, Watkins et al., 2016). For example, the lack of opacity in the reporting and analysis of the AI process is criticised (Clouder and King, 2015); and whilst selecting the affirmative topic is regarded as essential to the success of the AI process, it is unclear how, and by whom, it should be identified, accepted and adopted across an organisation (Bushe, 2011).

Previous healthcare research using AI has noted that some family care partners and staff find it difficult to move from a problem-based approach to a more positive assetbased approach (Seebohm et al., 2010, Trajkovski et al., 2013). 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). The deliberate bias and focus on positive experiences can result in important and meaningful stories, contextual factors and organisational understanding being overlooked or ignored (Oliver, 2005a). To counter this, reflexivity is integral to the process; providing a way of understanding why events that are perceived as negative or dysfunctional by some are viewed as positive by others (Fitzgerald et al., 2010, Oliver, 2005b). The use of AI in health and social care may be particularly appealing as reflection in and on practice is widely advocated and used in that context (Oliver, 2005a, Redmond, 2017).

In designing this study it was important to recognise that care homes are distinctive settings that generate unique opportunities (Luff et al., 2015). 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), although the energy in dream and design stages has been known to dissipate in the destiny stage leaving the work of implementation incomplete (Bushe, 2011, Reed, 2010). For AI to work in care homes, managers and the wider organisations must be willing to authorise their residents, staff and care partners to make any changes that are identified through the process. *My* Home Life (www.myhomelife.org.uk), a social movement that focuses on enhancing the experience and quality of life for people living, working and visiting in care homes, stresses the importance of supporting care home managers to facilitate relationship centred care for residents, and their staff and family care partners (Meyer and Owen, 2008, Owen and Meyer, 2012, Penney and Ryan, 2018).

Not all advocates of AI assume that it will produce concrete outcomes in practice. For example, Bushe and Kassam (2005) advocate ‘improvisation’ rather than implementation and this approach has been successfully employed in care homes by Dewar and Macbride (2017). They argue that implementation suggests that specific tangible outcomes are influenced and operationalised by managers. Instead, they propose that participants developing and pursuing a range of diverse ideas that employ participants throughout the AI cycle can lead to deeper organisational transformation and improve ongoing engagement. In this study therefore, AI is examined as the means of achieving culture change alongside the topic under investigation.

Care Home Readiness

Implementation science recognises that how an innovation is adopted is affected by an organisation's history, priorities, and context and its staff's readiness to participate. Five questions were asked of each care home to assess their interest and ability to participate in this study (Table 5). Questions developed by NHS and care home staff asked about the level of enthusiasm of staff and management, and whether there were pre-existing systems for staff to plan and discuss change together (Goodman et al., 2017). Care home readiness to participate in research is discussed further in 'Recruitment of Care Homes' later in this chapter and 'Organisational Culture' in Chapter 6 (Discussion).

Table 5: Care Home Readiness Questions - Taken from Goodman et al. (2017)

	Care Home Readiness Questions
1	Does this intervention align with care home priorities?
2	What evidence is there of senior management interest and enthusiasm for this intervention at organisation & unit level? Are they willing and able on a daily basis to take a leadership role in supporting the proposed *research*?
3	Do care home staff have enough "slack and flexibility" to accommodate the change into their current workload, is this recognised as core to their work?
4	How is change discussed (formally and informally) in the care home setting? Who needs to be involved in decision-making about what is being proposed and how it is implemented?
5	How well do existing care home training programmes and work schedules fit with what is proposed?

Using the 4D Cycle of Appreciative Inquiry

There are four distinct but interrelated stages of the 4D model, Discovery, Dream, Design and Destiny (Figure 5) (Cooperrider and Whitney, 2005). This '4D' cycle relies on participants contributing to multiple stages of the AI process. The four stages are described here. Data collection methods at each stage are detailed later in the chapter in the section 'Data Collection Methods'.

Flexibility is cited as a strength of AI, with the process able to be modified to suit the needs of the participants and their organisations (Clouder and King, 2015, Trajkovski et al., 2013). Cooperrider and Whitney (2005 p.25) acknowledge that "no two

Appreciative Inquiry processes are alike”. However, greater transparency in reporting moderations to AI process and practices is called for to identify the most effective change levers within the process (Bushe, 2011, Reed, 2006). I elected to adapt the 4D cycle by combining the discover and dream stages into a single stage due to an awareness of the potential cognitive load and time constraints for participants (Hall et al., 2009). Modified AI approaches have previously been successfully used in care home research (see for example; Amador et al., 2016, Mathie et al., 2012b).

Transferability is not an aspect of AI that is widely discussed – even in methodological critique (Bushe, 2011, Clouder and King, 2015). This may be due to the centrality of the participants in the design and implementation process, meaning that each AI is context driven and outcomes are specific; implementing distinctive ideas with each reaching unique destinies. However, Transparency in the application of the five core principles of AI (Table 4) can aid transferability of results (Bushe, 2011, Reed, 2006). Here, the five core principles are woven into the process so that they are inherent throughout the AI and are integrated in underpinning the study design. For example, interview questions use positive language to seek individual’s perspectives through storytelling; combining the constructionist, poetic and positive principles. The stories are then used as a basis for participants engaging in dreaming and designing a future that aligns with the outcomes that reflect their positive experiences, hopes and wishes. This shaping of future behaviours combines the simultaneity, anticipatory and positive principles.

The 4D cycle of Appreciative Inquiry

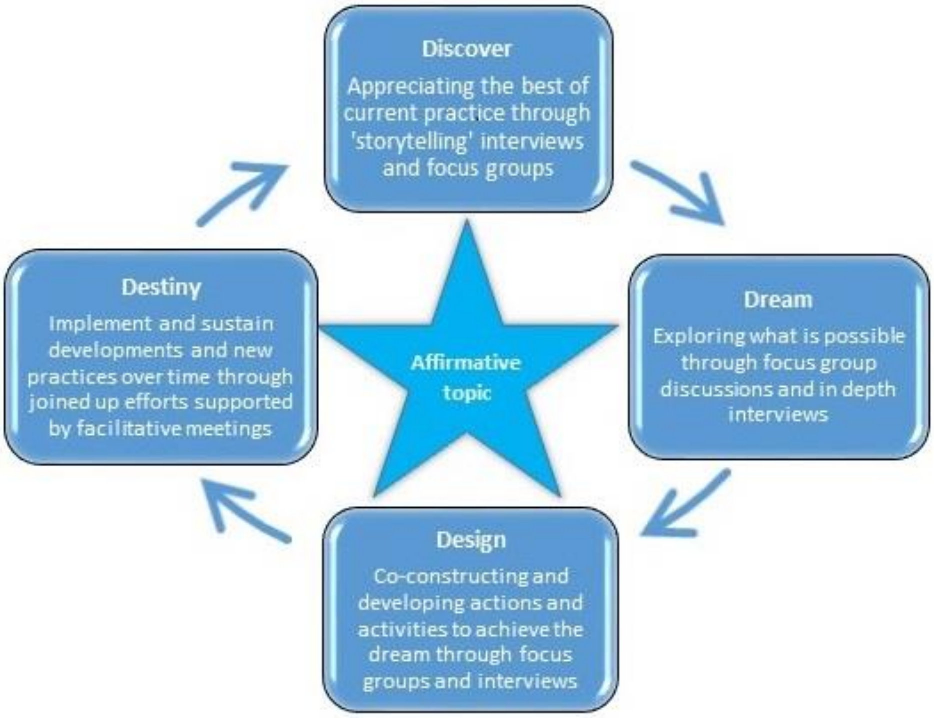

Figure 5: The 4D Cycle of Appreciative Inquiry (Cooperrider and Whitney, 2005)

Discover

The purpose of the discovery stage is to understand the best of *what is*. Cooperrider et al. (2008) advocate the use of observations and interviews to collect strength-based background data that identifies positive practice. Relationship building is important and this can be achieved through sharing stories and experiences, and noting what looks and feels good for the individual participants (Bushe, 2011, Cooperrider et al., 2008). It is important to commence this stage by designing a study protocol. Mine was informed by the review findings and framed by the guidelines from Watkins et al. (2011) on developing an AI study. The protocol detailed the study aims, ethics, data collection methods and schedules.

Dream

The ‘Dream’ stage explores the themes that emerge in the discovery stage and uses them to encourage people to think beyond what is ordinarily possible (Cooperrider et al., 2008). This stage is about further developing relationships between participants through the identification of common aspirations (Bushe, 2011). Participants have the opportunity to recognise the importance of interdependencies and imagine how cooperation could lead to improved shared decision-making based on their best past experiences (Bushe, 2011, Cooperrider et al., 2008). Participants' Dream ideas inform the 'Design' stage of the process (Clouder and King, 2015, Cooperrider and Whitney, 2005).

Design

The design stage can be used to "bridge the best of what is with collective aspiration of what might be" (Cooperrider and Whitney, 2005 p.29). The participants are therefore invited to explore the 'Dream' ideas in the context of the discovery stories, and hone and develop them into more practical and potentially manageable actions and innovations that structures and relationships are in place to facilitate (Watkins et al., 2016). 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).

Destiny

Destiny is the final stage of the 4D cycle and provides the opportunity to implement and sustain the coproduced ideas. It was originally called Delivery (Cooperrider and Whitney, 2005) but was changed to create a conceptual difference from the language and traditional assumptions of change management theory (Clouder and King, 2015). Bushe (2011) advises that this stage is the most contentious amongst AI advocates because participants '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 recognised and valued. However, this raises questions about whether empirically tested evidence is perceived as more or less important than practice-based learning and development. Watkins and colleagues (2016) highlight that measures, standards and benchmarks can be integrated into AI, although it rarely appears to be the case (Amador et al., 2014) and can detract from the participants leading the process.

Ethics

This section considers the ethical issues that arise from performing research with people living with dementia and how they were addressed in this study. An overview of the focus of the ethics application precedes the processes of assessing and negotiating access to the care homes. The gatekeepers' roles in protecting individual participants are discussed followed by the multiple approaches used to gain consent for observations of, and interviews with, people living with dementia and communication difficulties who may have limited or fluctuating capacity to consent.

The ethics application was particularly detailed in relation to access and consent processes, confidentiality and risk/benefit ratio. These elements were considered in the context of legal frameworks and ethical guidelines (Hall et al., 2009). Historically research has largely excluded frail older people and those living with dementia due to their vulnerability, impaired ability to provide informed consent and ethics committee refusal (Davies et al., 2014, Dewing, 2002, Edvardsson et al., 2017, Hellström et al., 2007, Liamputtong, 2006). Research including people with limited or fluctuating capacity must therefore be approved by an ethics committee with responsibility for people lacking mental capacity (Health Research Authority, 2017). This study protocol and all supporting documentation were submitted for ethics committee review and given a favourable opinion by the North West Research Ethics Committee (REC) (IRAS reference number: 226515).

Dementia Care Homes

For older people living in care homes, there are particular 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. Therefore, studies with vulnerable people in care homes 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 decisions (Liamputtong, 2006). This responsibility is recognised as having 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 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 but concerns have been raised that older people with limited capacity, may feel coerced to participate in research (Hall et al., 2009, Mcmurdo et al., 2011) and that care home residents may ‘unthinkingly’ agree to participate in studies to pass the time or increase human contact (Liamputtong, 2006, Maas et al., 2002). Although Tooke (2013), argues that the effects of dementia may make people less socially constrained and more likely to express their opinions, meaning they would not feel obliged to agree to participate in research if they did not want to.

The protection of an individual's privacy, avoiding unnecessary intrusion and maintaining confidentiality were therefore key for this study. To ensure these ethical issues were considered, data were only collected in shared spaces within the care homes (for example; lounges, dining areas, entrance halls, gardens and corridors). Historically, some researchers (see for example, Martin and Younger, 2000a) referred to these spaces as "public areas". However, a shared space in a care home is like a shared space in an individual home, and therefore not public. I only entered private spaces (such as bedrooms and staff rooms), by explicit invitation of the occupants and never observed intimate care.

I was mindful that residents' acceptance of my presence could have been misconstrued as implied consent to being observed (Department of Constitutional Affairs, 2007). At the beginning of each observation period I explained the purpose of my presence to all residents, staff and visitors present and asked if they were happy for me to observe them. This information was repeated for anyone newly entering the space and existing participants if they questioned my presence at any time during an observation period. I would have ceased observing the individual or area (as appropriate) immediately if anyone had exhibited discomfort or distress associated with my presence, such as verbal or physical acts outside of their normal behaviours.

I specifically sought to recruit dementia care homes that were willing, and assessed as able, to take part in research. This was important because uptake of innovations is likely to be improved when contextual factors, such as culture and leadership are considered, although the specific aspects of leadership that are important is inconclusive (Goodman et al., 2017) (Table 5).

Accessing Participants

In England, proxy consent is not acceptable (Department of Health, 2009). It was important then, to ensure that people who were unable to provide ongoing informed consent could participate in this research if they chose to, whilst safeguarding them as potentially vulnerable (Department of Constitutional Affairs, 2005, Health Research Authority, 2017b). The REC assesses the ethical competence of the research team and the rigour of the proposed study. Whilst the ethical review process cannot predict difficulties which could arise during fieldwork (Atkinson, 2009, Fahie, 2014), it can appraise the perceived ethical awareness and capability of the researcher in the field (Iphofen, 2013). This process, along with the introduction of the MCA (Department of Constitutional Affairs, 2005) has promoted safe access to people living with dementia in care homes.

The care home managers acted as gatekeepers and introduced the study to the homes, staff and residents following ethical approval and a formal process, including presenting the study protocol to senior staff. The gatekeepers were assured that any safeguarding related disclosures raised would be dealt with following the care home guidelines and in line with the Care Act (2014). Respecting the gatekeepers' advice and support was invaluable and in addition to facilitating access, potentially improved the relationship with the researcher (Luff et al., 2015). The gatekeeper process highlighted a paradox, in that a study focused on shared decision-making with people living with dementia, was reliant on individuals overseeing the decision-making process to facilitate access to the potential participants. To continue to promote the social citizenship and equality of access to research for people living with dementia (Bartlett and O'connor, 2010), gatekeepers may need opportunities to develop their skills and understanding of residents desire to participate in research and ways to facilitate this that safeguards all the individuals and organisations involved.

Consent Processes

Consent was taken to mean that the participant understood that they were taking part in a research project, what it involved, how confidentiality would be managed and that the research outcomes would be shared (Hirschman et al., 2005). Study information and consent forms were presented in a variety of formats and multiple consent processes were used to promote inclusivity and choice, which Luff and colleagues (2011, 2015) consider to be a thorough and effective approach. The processes for obtaining consent can be seen in Table 6.

Table 6: Consent Processes Employed

Consent process	Participant living with dementia	Care staff participant	Care partner participant
Opt-out (observations only)	✓	✓	✓
Ongoing informed consent	✓	✓	✓
Process consent	✓		
Consultee assent	✓		

Obtaining consent was time consuming; which is well recognised in care home research (Hall et al., 2009). Written study information was supplemented with face-to-face discussions with prospective participants (Brown-Wilson, 2009). Participant information sheets and consent forms were written in plain English and residents information sheets were formatted with a larger font and illustrated using a resource developed with people with communication disability (Hall et al., 2009, Pearl and Cruice, 2017) (Appendix 4). I answered all questions and anyone who chose to participate provided consent within a few days. All the staff and residents identified as potential participants that were able to complete consent forms did so without expressing any concerns. Although participants were told (and reminded) that they could opt out at any time by speaking to their staff or family care partner, not attending their interview or focus group or by ceasing their interview, nobody did.

Information posters and leaflets were available on every unit in each care home. I offered different levels of consent depending on the individual participants ability at the time, and on the data collection method. For example, some participants were observed but did not participate in interviews or focus groups. Researchers working with people living with dementia must be fully trained in assessing capacity (Mcmurdo et al., 2011) and Dewing (2007) demonstrates concern about the ability of novice researchers to implement complex consent processes. As a qualified and experienced nurse and best interest assessor, my knowledge and skills of mental capacity assessment and reflective practice, informed the process. Observations were undertaken on an 'opt-out' consent basis (Lawton, 2001, Martin and Younger, 2000a).

Ensuring that people had an opportunity to withdraw, or not be observed, relied on my assessment in addition to individual and staff feedback on people's responses and behaviours associated with my presence. Observations were partly designed to prepare for process consent and to help the staff and residents to be comfortable with my presence (Clissett et al., 2013, Mulhall, 2003). Where I was left alone with a resident who I was unsure had the capacity to opt out I excused myself from the room and continued my observations in another location. I documented this type of decision each time it was made during data collection.

I employed staff members’ expertise and knowledge of individuals to support my assessment of whether the resident had the capacity to provide consent at that time. I discussed participation directly with the resident and only continued discussions about their participation with a staff or family care partner if the person asked me to, 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 sought from all participants who had capacity to provide it for interviews and focus groups. Consent was acceptable verbally and non-verbally as well as in writing. Informed consent requires considerable amounts of cognitive and executive ability (Mcmurdo et al., 2011) and obtaining written consent from care home residents may be inappropriate. Instead I spent “time with each person, reiterating the details of the study and ensuring participants had a reasonable understanding before continuing” (Luff et al., 2011 p. 13-14). Verbal consent was audio recorded and non-verbal consent would have been witnessed if used.

Process consent (Table 7) was used to offer people living with dementia and limited capacity, the opportunity to be involved and included in research that may previously not have been considered possible (Dewing, 2007, Dewing, 2008). Process consent relies on preparation including; liaising with gatekeepers, understanding existing capacity assessments and observations. It is a recognised method where consent is continually sought and renegotiated (Dewing, 2007, Gelling and Munn-Giddings, 2011). A gatekeeper and I assessed whether the person was giving consent to participate and whether their consent was on-going throughout the interview or focus group.

I made provision for the use of personal consultees at the request of the Research Ethics Committee (REC). Personal consultees are usually a care partner (family member or close friend) who know “the person who lacks capacity in a personal capacity who is able to advise the researcher about the person who lacks capacity’s wishes and feelings in relation to the project and whether they should join the research" (Department of Health, 2008 p.3). This increased the number of people able to participate in the study.

Throughout all interactions with participants my aim was to: speak slowly and clearly, repeat information where necessary and ask open questions (Department of Constitutional Affairs, 2007 Chapter 3). Because all the residents who participated had some communication or language difficulties I had to be particularly sensitive to non-verbal cues, mood, para-verbal and behavioural communication that could suggest changes to their consent (Hubbard et al., 2003). If the staff or family care partner, or I had noticed anything that could have represented a change to their consent status, the observation or interview would have been stopped and consent revisited.

I included any resident who expressed an interest in participating in the study, regardless of their level of cognitive impairment or communication difficulty (Mozley et al., 1999) if they were able to provide consent or their consultee, assent. This inclusive approach was intended to reflect the principal of equality inherent in the AI methodology and aligned directly with the purpose and focus of my study. I worked with the care home residents, staff and family care partners to support people to demonstrate their choice as to if, and how, they would like to participate, making an implicit statement about the equal value of all participants (Godwin, 2014). The research process was then tailored to each individual or groups needs and wishes.

Information about this study was on the door and notice board of every unit, as well as the reception areas, in both homes. Residents' personal information was kept secure and was rarely discussed openly in my presence. There were occasions when I requested demographic information about a resident who had consented to participate in an interview but were unable to provide information about, for example, their age and a staff member offered me the residents file. I advised them that I did not have ethical clearance to access the residents' notes and they looked the information up for me, which added to their workload. On reflection I should have included access to the resident participants records' in my ethics application.

Table 7: The Process Consent Method – Taken from Dewing (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 explores existing capacity assessments and opinions, recognising that capacity is time and decision specific. The researcher can tailor creative and sensitive methods to include the individual. If the individual does not have capacity to consent the researcher must establish to what extent the person can make their own choices, and how they feel about the research. Consent established in this way relies on a more holistic perspective of the person and not on conventional cognitive emphasis of understanding, retaining and weighing of information. It is not informed consent and must be revisited 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: On going 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.

Recruitment

Inclusion Criteria

Recruitment was shaped by the assumptions of the AI approach and the resources available for the study. This meant that a maximum of 2-3 care homes could be involved. It also took as its starting point that the care homes would be willing to participate in principle. Inclusion criteria (Table 8) were designed to include research participants most likely to be involved in sharing everyday decisions in care homes. Exclusion criteria were: The Local Authority or care home manager requesting exclusion on safeguarding grounds, people considered to be at the end of their life by their health or care workers and staff or family care partners if considered necessary on safeguarding grounds.

I elected to narrow my inclusion criteria to people living with dementia and communication difficulties because, all forms of dementia are known to affect both expressive and receptive language abilities including behavioural impairments that affect communication (Bourgeois et al., 2010, Potkins et al., 2003, Small and Gutman, 2002). In addition, sensory impairments affect more than half of older people with cognitive impairment, and these too are understood to impact on effective communication (Janicki and Dalton, 1998). The systematic review (Daly et al., 2018) showed that shared decision-making appeared to be reliant on the relationships between people living with dementia and their staff and family care partners, and that in turn was significantly dependant on people’s ability to communicate effectively (Clarke and Davey, 2004, Godwin, 2014, Milte et al., 2015, Murphy and Oliver, 2013).

Recruitment of Care Homes

Four care homes were approached with a view to recruiting two homes. Care homes representing each of the Care Quality Commission (CQC)[2] ratings were approached based on a suggestion from the patient and public involvement (PPI) group linked with the university. Two of the homes approached were care homes with nursing and two without nursing. All four homes were registered for dementia care. I used purposive sampling; making use of my existing professional networks and positive pre-existing relationships with care home managers and staff to identify care homes thought to present a willingness to participate in research activity. Data suggests that the number of care homes owned and run by local government has reduced dramatically in recent years meaning that just over half (55 per cent) of care home residents in private sector care beds are funded by local authorities, a small proportion (6 per cent) are funded by the NHS with the remainder being self-funded (Laing and Buisson, 2009). Of the care homes approached for this study, two represented predominantly Local Authority funded beds in not-for-profit organisations

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[2] The Care Quality Commission (CQC) is the regulatory body for health and social care providers in the UK.

and two homes represented for-profit organisations with predominantly privately funded beds.

From the four homes identified and approached, three homes expressed an interest in taking part in the study, but one was unable to negotiate participation through their organisational research and development committee. The remaining homes, were assessed through the care home readiness assessment process (Goodman et al., 2017) (see Table 5 and 'Care Home Readiness' in this chapter and *'*Organisational Culture*'* in Chapter 6). Both homes recruited to the study were care homes with nursing and both supported older people with a wide spectrum of types and levels of dementia. However, whether or not the home included nursing staff this was not considered relevant to the topic because care staff, rather than nurses, are likely to be most involved in everyday shared decision-making. At the time of recruitment, the two care homes who agreed to participate were rated either good or outstanding by the regulator.

When I first engaged with the care homes, I identified key stakeholders (such as managers, residents and care staff) who considered shared decision-making to be interesting and important to their organisation (Barrett and Fry, 2005, Bushe and Kassam, 2005). Each care home identified a lead that would be responsible for co-ordinating the research and liaising with me. Each care home has been given a pseudonym.

Table 8: Inclusion Criteria for Care Homes and Participants

Inclusion Criteria	
Care Homes	To be eligible for the study care homes must; • be registered with the Care Quality Commission (CQC) to deliver residential dementia care, with or without nursing • have more than 30 beds • have sufficient numbers of residents living with symptoms consistent with dementia and communication difficulties (>10)
People Living with Dementia	People living with a dementia diagnosis and those identified by care staff as displaying symptoms consistent with dementia if they also have communication or language difficulties including (but not limited to); • aphasia • apraxia of speech • hearing and/or sight impairment • echolalia • word finding difficulties Participants must have been resident within a care home study site for more than one month prior to their inclusion in the project to allow them time for transition from their previous living environment.
Care partners	The care partner must be a relative or close friend of a study participant living with dementia and language or communication difficulties and must visit the home regularly (> once monthly).
Care staff	Care home staff who regularly (>twice weekly) undertake at least two activities that support everyday care needs (Cadieux et al., 2013) of people living with dementia, for example; • Personal hygiene care (e.g. washing, bathing, showering) • Hair care, nail care • Assistance with eating/drinking (including choosing what to eat or drink) • Mobility (e.g. transferring from one place to another, walking, getting in and out of bed) • Continence care (e.g. toileting, changing pads, emptying catheter bags) • Administering medication • Engage in meaningful daily activities (e.g. exercise, playing cards, reading, discussing family life or current affairs, reminiscence, faith-based activities) • Sensory engagement (e.g. use of massage, visual and/or aural stimulation
Care Home Managers	The managers and/or assistant managers of study sites will be eligible to participate in the project.

Recruitment of Staff and Residents

Each care home lead was supported to recruit participants from their home in their own way, within the inclusion criteria and parameters of the study protocol. Luff et al. (2015) discussed selection bias and the role of care home managers as gatekeepers; they note that gatekeepers may propose the “most able and possibly most ‘positive’ or ‘compliant’ residents’” to participate in research (Luff et al., 2015 p.17). I therefore explained to the care home managers and staff that all care home staff and residents that met the inclusion criteria and demonstrated an interest in participating, would be considered eligible for the study.

To maximise organisational outcomes from the AI process I aimed to recruit a sample offering maximum learning opportunities from each home. My sample of up to 14 staff members, 10 people living with dementia and communication difficulties[3] and their care partners, from each home reflected sample sizes and types from previous health and social care AI studies. Although Watkins et al. (2016) note that some studies do not state sample sizes (e.g. Lazic et al., 2011, Shendell-Falik et al., 2007), numbers in other studies ranged from 12 participants in each site (Clarke et al., 2012, Kavanagh et al., 2010) up to 74 participants across three care home sites (Amador et al., 2014).

Whitney and Trosten-Bloom (2010) identify different ways of engaging organisations in AI interventions. These range from an individual or small representative group, to all (or most) of the organisation participating in the entire 4-D cycle. The AI literature leans towards greater engagement leading to more transformative change (Bushe, 2011, Bushe and Kassam, 2005, Cooperrider et al., 2003b). However Barrett and Fry (2005) discusses this in terms of engaging the ‘right’ people rather than the size of the sample. My sample was designed to be realistic and allow for the flexibility required in recruiting in care homes (Luff et al., 2015) and to reflect guidelines for selecting sample sizes for qualitative PhD studies (Marshall et al., 2013, Mason, 2010).

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[3] Less people living with dementia and communication difficulties were approached due to the additional time that it was anticipated would need to be allocated to ensure that interviews and focus groups were tailored to their individual needs.

I chose not to measure potential resident participants cognitive ability or ‘level’ of dementia with, for example, a Mini Mental State Examination (MMSE) (Folstein et al., 1975). This decision was taken because;

1. this study focuses on decision-making. Reviews of cognitive assessment tools not only found inconsistency in clinical judgement, but also the lack of accuracy in the MMSE to predict decision-making ability in cognitively impaired older adults (Kim et al., 2002, Lai and Karlawish, 2007).
2. the first principle of the Mental Capacity Act (2005), is the assumption of capacity (to make a decision) unless it is established otherwise.
3. capacity is time and decision specific (MCA, 2005). Therefore, a clinical measure of cognitive ability undertaken at another time or about another subject is not necessarily relevant to the decision-making in question.

Care Home 1 ‘Treetops’

Care home 1 invited me to an all staff meeting where I presented the research and eight care staff immediately volunteered for the study. This type of participant self-selection is seen as positive for ongoing engagement (Watkins et al., 2011). The manager then asked the staff to identify potential resident participants and directed them to me to discuss the study and find out more information. Care partners of residents included in the study were invited to participate either by the resident themselves, the care home staff or the researcher.

Care Home 2 ‘Eden Valley’

In care home 2, I was invited to meet with the clinical lead who identified members of staff she felt would be most appropriate to participate the study. The clinical lead then asked the staff that she had nominated to identify residents that met the inclusion criteria and might be interested in the study. Care partners of included residents were invited to participate either by the resident, the care home staff or the researcher.

Data Collection Methods

The data collection involved face-to-face quality of life and communication questionnaires, semi-structured observations, interviews, focus groups, and participant engagement throughout the AI cycle. I employed multiple data collection methods to maximise access to the stories and ideas of all the participants and to enhance inclusion of as many different perspectives and ‘voices’ as possible (Hubbard et al., 2003). This also enhanced validity by using one method to corroborate another (for example observations confirmed participant narratives) (Fusch and Ness, 2015, Moran-Ellis et al., 2006, Pope and Mays, 2006).

Each data collection method is presented in Figure 6, with how it was organised to capture shared decision-making events that occurred between people living with dementia and communication difficulties, and their staff and family care partners; and how the data collected fed into, and progressed through, the stages of the 4D cycle[4].

Data Collection Process Diagram

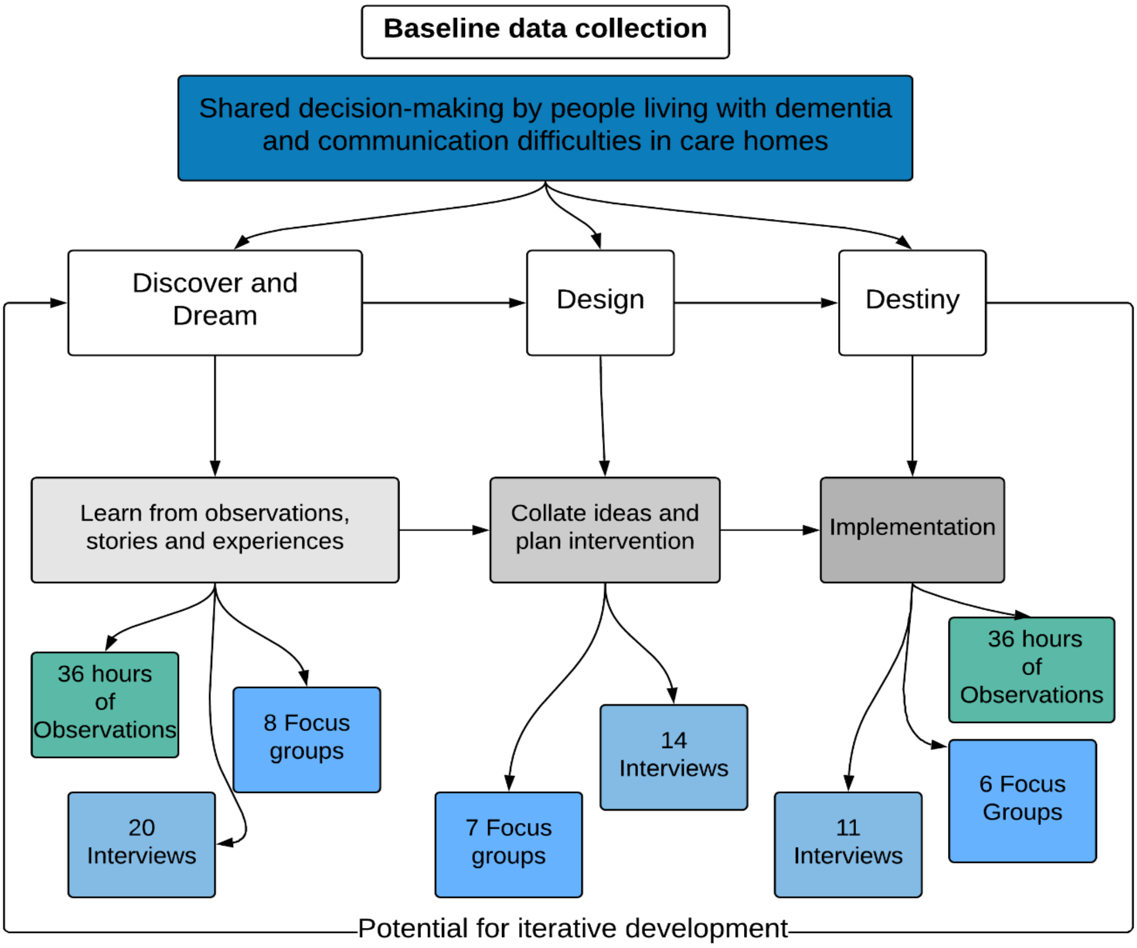

Figure 6: Data Collection Process

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[4] Interviews that fulfilled more than one stage in the 4D cycle are counted in each stage covered.

Demographic Characteristics

To understand the profile of the those involved in the study and describe the sample in each care home, I collected demographic data (Table 9). All participants were told that the information was only for research purposes. If residents were unable to give the information, or they wanted the information corroborated, I asked if they were happy for me to collect the information from the care staff.

Table 9: Participant Demographic Data Collected

Demographic Data Collected			
Information Requested	**Resident**	**Staff**	**Family**
Gender	✓	✓	✓
Age	✓	✓	✓
Ethnicity	✓	✓	✓
Time since dementia diagnosis	✓		
Communication difficulties	✓		
Care partner involved and relationship	✓		
Unit (where the participant lives, works or visits)	✓	✓	✓
Time in job		✓	
Time resident	✓		
Job role		✓	
Length of relationship with resident		✓	✓
Dementia training		✓	
Communication training		✓	

Together with a care partner or member of staff, I completed the Dementia Communication Difficulties Scale (DCDS) (Murphy et al., 2007) for all participants living with dementia. The tool was designed to help care staff and partners to understand the levels and types of communication or language difficulty the person was experiencing and therefore how best to support and communicate with them. I used this tool to promote involvement of people who might otherwise be marginalised by their depleted ability to communicate, in keeping with my participatory approach. I also planned to use the DCDS scores to identify whether the level of dementia related communication difficulties impacted on decision-making involvement. The tool includes statements based on common communication problems for people living with dementia and is scored on a five-point scale from ‘never’ (score 0) to ‘always’ or ‘says too little for me to judge’ (both score 3). An example statement is ‘They have difficulty coming up with words’.

Each participant identified as living with symptoms reflecting dementia and a communication difficulty was asked to complete a quality of life score, along with their staff or family care partner. There are several quality of life measures available for people living with dementia, these vary in quality and suitability. I considered the Quality of Life in Alzheimer's Disease (QOL-AD) measure (Logsdon et al., 1999) and the Dementia Quality of Life instrument (DQoL) (Brod et al., 1999) as both were developed in consultation with people living with dementia and involve self-report tools thought to support participants in taking an active role in the research. Both have been widely used and compared (Brown et al., 2004, Edelman et al., 2005, Ready and Ott, 2003). This data was to be collected pre and post AI intervention with the aim of identifying if there were changes in quality of life scores among participants living with dementia and communication difficulties.

I selected the Quality Of Life in Alzheimer’s Disease (QOL-AD) questionnaire (Logsdon et al., 1999) because it was more concise and compared the perspectives of the person living with dementia and the staff or family care partner in assessing an overall quality of life score including the physical, mental, social and functional aspects. It is thought to be acceptable for use through moderate to severe dementia (Brown et al., 2004, Hoe et al., 2009). The 13-item scale is rated using a 4-point scale (poor, fair, good, and excellent). Post AI QOL-AD scores were not recorded, which is explained later in this chapter in *‘Quality of Life of People Living with Dementia’* and in the ‘*Strengths and Limitations’* section of the Discussion Chapter.

Observations

Observation is a useful way of understanding what actually happens with minimised participant bias (such as poor recall or participants desire to present themselves well)(Fitzpatrick and Boulton, 1994). Observations are widely advocated as a useful method of understanding the context of care homes, especially the specifics of day-to-day routines and social dynamics (see for example, Brown-Wilson, 2009, Luff et al., 2011). Although Luff and colleagues (2015) suggest that researchers should be well supported throughout fieldwork due to the potential emotional burden involved. Hubbard (2003) advocates observation of people living with dementia and communication difficulties as a way of capturing their experiences and sharing their perspectives. This aligns well with the use of observations in the discovery stage of the AI 4D cycle to note what looks and feels good for participants and as a way of building a strengths-based picture of current practice (Bushe, 2011, Cooperrider et al., 2008, Watkins et al., 2016).

The observations were structured and carried out in the same way for both the discovery and destiny stages of the 4D cycle. Discovery stage observations were used to understand how shared everyday decision-making was being employed to support, organise and deliver positive care experiences in each home. The observations at the end of the process (destiny) were designed to feed into the evaluation of the AI process (Van Der Haar and Hosking, 2004).I adopted a non-participant observer role that allowed me to be present in the care homes as an ‘accepted outsider’, which Fitzpatrick and Boulton (1994) argue may be particularly useful in describing and conceptualising working practices in healthcare. This, they argue, is because every day routines may be so familiar to participants that they are beyond their conscious awareness.

I am aware that my professional background as a Registered Nurse made it impossible to escape an element of professional judgement in my observations (Pope and Mays, 2006, Reed and Procter, 1995) and would impact on the way that I experienced and interpreted the care that I observed.

Observation Procedures

I completed six, three-hour observations focusing only on shared everyday decision-making practice in each home as part of each of the discovery and destiny stages of the 4D cycle. Evidence suggests three hours is long enough to minimise the effect of the presence of the researcher on normal routines and behaviours in a busy care environment (Clissett et al., 2013, Mulhall, 2003). All observations took place in shared areas within the homes (e.g. lounges, dining rooms, corridors, gardens and reception areas).

Observations were undertaken between 7am and 9.30pm in each site. These hours were chosen to include the period when a range of interactions and daily activities occur, when residents are more likely to be in communal spaces, and to include staff handover between shifts. In keeping with the non-participant observer role, I did not intervene in care delivery or interact with participants unless they instigated the interaction.

Purpose of Observation in the Discovery Stage

Observations of current practice were incorporated into the *discover* stage of the 4D cycle to learn more about each care home setting and the people living, working and visiting there. More specifically to:

1. Help people living with dementia in the care home feel more comfortable with me and to gain their trust (Boyle, 2014, Dewing, 2008, Mckillop and Wilkinson, 2004).
2. Notice the key everyday decisions that people living with dementia and communication difficulties make and share with their staff and family care partners in care homes
3. Begin to understand how care home staff recognise when a person living with dementia and communication difficulties demonstrates a desire to be included in their decision making, and the skills, resources or personal characteristics they use to facilitate that.
4. Prepare for the process consent method used for interviews and focus groups with those people living with dementia and communication difficulties who had limited or fluctuating capacity (Dewing, 2007, Dewing, 2008).
5. Familiarise myself with how participants' present under 'normal' everyday circumstances. Understanding their regular behaviours, facial expressions and interaction builds a layer of relational appreciation as well as insight into their usual methods of communication (Hubbard, 2003). This is also considered to be the first step in building a relationship of trust (Dewing, 2002).
6. Identify contextual factors associated with each care home; their custom 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 observations to identify examples of existing shared decision-making interactions and any resulting actions and behaviours (Mulhall, 2003) that could then be fed into the interviews and focus groups. I initially considered using Dementia Care Mapping (DCM) (Kitwood and Bredin, 1997) as an observational tool.

DCM is a tool that records ‘positive events’ and ‘personal detractors’ where staff interact positively with people living with dementia, or negatively for example mockery or infantilisation. DCM, however, provokes anxiety in some staff (Brooker et al., 1998) which contradicts the philosophy of the AI methodology.

I identified Feinberg and Whitlatch’s (2002) Decision Making Involvement (DMI) scale through the systematic review, and initially used it to structure my observations. Careful objective recording is essential in observational research (Fitzpatrick and Boulton, 1994, Silverman, 2013). I planned to count and code the shared-decisions that I saw against the DMI (Appendix 6) and grade them on a four-point scale (0 = not at all involved; 1 = a little involved; 2 = fairly involved; 3 = very involved). Additional notes were used to include who instigated the decision and any personal characteristics, tools and resources used to facilitate the interaction.

It became apparent, however, that the tool did not capture the complexity and aggregated nature of the decisions that were being shared, or the number of people involved. For example, during a chair-based activity session there was a break and staff offered each resident a drink, they initially used an open question ‘would you like a drink?’, then broke that down depending on the person’s answer. Several staff were involved in this process and I found it difficult to capture multiple decisions being shared by multiple people. Observing in a communal environment meant that the decision-making process could be a group or individual process. The tool also included decisions that were less relevant to people living in care homes (such as what foods to buy).

Based on the limitations of the DMI scale in this context, I used the observation schedule (Appendix 5) to maintain the focus of my observations on shared everyday decision-making episodes. This approach has successfully been used to structure the AI discovery stage by other researchers (Trajkovski et al., 2013). 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 residents and their staff and family care partners. These notes on how shared everyday decision-making opportunities were created and recognised were recorded in addition to any resulting outcomes of the decisions. I recognise that my field notes were inevitably subject to observer bias (Fitzpatrick and Boulton, 1994) and this was addressed in supervision and through maintenance of reflective diaries.

Purpose of Observations in the Destiny Stage

Observations of current practice were also incorporated into the *destiny* stage of the study to understand more about how each care home and the people living, working and visiting there had used the 4D cycle. More specifically to:

- Evaluate whether care home staff developed or changed the way that they used skills, resources or personal characteristics to facilitate shared everyday decision-making opportunities as a result of the AI.
- Explore whether any of the *dream* ideas had been implemented in the care homes and if so, how they were affecting shared everyday decision-making practice.

Interviews and Focus Groups

To understand individual and shared experiences of everyday decision-making and identify emerging ideas and themes semi-structured, in-depth interviews and focus groups were organised for all four stages of the 4D cycle. All participants were given the opportunity to be interviewed individually or as part of a group. People living with dementia were also given the choice of having a care partner present (either a family member or care staff), in a location where they felt safe and comfortable (Mckillop and Wilkinson, 2004). The questions followed consistent themes but were tailored to each participant group (residents, care partners and staff). They referenced the context and routines of each care home and paid careful attention to individuals' language and capabilities.

The interview and focus group schedule (Appendix 3) was positively framed using the Cooperrider and Whitney (2005) 4D cycle of AI. The structure was used to maintain focus whilst allowing the participant(s) flexibility to express their experience (Pope and Mays, 2006). This was considered particularly important for people living with dementia and communication difficulties. It enabled me to use the person's own vocabulary or communication method to reframe questions or ask for supplementary information (Hubbard et al., 2003, Pope and Mays, 2006).

At the *dream* stage participants were asked to imagine how they could make shared decision-making even better. In the *design* stage, participants were reminded how important their input had been. At this point all the *dream* ideas were fed back to everyone. This process allowed for cross fertilisation of ideas between individuals, groups and care homes. Participants who were being interviewed individually were able to participate in the 'group think' aspect of the AI process and appreciate the thoughts and ideas of others whilst exercising their choice to be interviewed individually. The *destiny* stage was designed to understand the participants own evaluation of the AI process and any changes that had taken place as a result.

Interview and Focus Group Questions

The questions that guide the AI process, and the language used, are considered to be crucial (Grant and Humphries, 2006). For example, a direct correlation between the positive nature of the questions and the success of an AI intervention has been suggested (Bushe, 2011, Cooperrider and Whitney, 2001). In keeping with the AI principles and the 4D cycle, the questions in the discover and dream stage were designed to encourage participants to engage in storytelling and share their 'best' experiences of shared everyday decision-making. All the questions were framed to encourage participants to relay positive stories whilst being careful not to shut down any conversations that were less positive, which could have left participants feeling disregarded or that their input was unimportant (Bushe, 2011, Grant and Humphries, 2006).

Interviews

A key feature of in-depth interviews is the opportunity for detailed investigation into an individual's personal perspective. Ritchie and colleagues (2013) argue that they are the only way to collect sensitive or complex data within the context of personal history, circumstance or experience.

The skills and judgement of the interviewer for in depth interviews are recognised as essential by many methodologists (see for example, Silverman, 2013). Interviewers need to be able to; ask open questions and then probe for further information if required and demonstrate interest in the respondent and what they have to say (Fitzpatrick and Boulton, 1994, Ritchie et al., 2013, Silverman, 2013). However, this is seen to be less important in AI interviews, where participants are sometimes employed to interview one another (Edvardsson et al., 2017, Reed, 2010). I chose to undertake the interviews myself to maintain equity in the process and to minimise time and cognitive pressures on participants.

Despite having experience of interviewing care staff, I have however, never formally interviewed people living with dementia and communication difficulties for research purposes. I therefore followed advice and methods described by a person living with dementia and researchers with experience in this field (Hubbard, 2003, Mckillop and Wilkinson, 2004). I asked participants if they had particular ways of communicating or used any aids and took picture cards to each interview for the person to use if they chose to. Some residents and their family care partners chose to complete the entire 4D cycle of AI in a single interview or focus group. Whilst this is not in keeping with the traditional approach, I felt that it was important to respect the participant and their needs and rights to adopt a “unique form of participation” in the AI process (Grant and Humphries, 2006 p. 411).

Focus groups

In AI the combination of people in a focus group is important for developing consensus in care homes as participants discuss and reflect on their experiences (Reed and Payton, 1997). The discussion is considered essential for participants to understand one another’s perspective (Cooperrider and Whitney, 2005). I was mindful of potential pre-existing power relationships between care staff within the homes (Reed and Payton, 1997) and made an effort to involve all participants in the discussions. The facilitator has less overall control in focus groups than in interviews (Fitzpatrick and Boulton, 1994), which despite proving challenging at times, was positive as it reduced my influence on the data (Fitzpatrick and Boulton, 1994, Ritchie et al., 2013, Sofaer, 1999).

Very little has been written about the specific competencies required of the researcher in facilitating AI (Bushe, 2011, Watkins et al., 2016). For me, important facilitations skills included supporting and enabling people to exchange their views and reflect on their experiences. This provided an opportunity for participants to explore and refine some of their attitudes and behaviours within the AI cycle (Cooperrider and Whitney, 2005, Pope and Mays, 2006, Reed and Payton, 1997, Ritchie et al., 2013).

Using focus groups enabled me to collect a great deal of data in a short period of time. Focus groups were organised to maximise a combination of participants from different units (Table 10). This enabled participants to share stories with people that they would not ordinarily spend time and appreciate one another's perspective, collaborating through the AI process (Cooperrider and Whitney, 2005, Hubbard et al., 2003, Staniszewska et al., 2011). The focus groups consisted entirely of care staff, except for one that comprised of three people living with dementia (supported by one member of staff). Groups were structured to encourage reflection on progress so far as well as new thoughts and developments.

The focus group for people living with dementia was facilitated with additional care and sensitivity recognising that the stimulation could overburden individuals (Kempler, 1991, Potkins et al., 2003) and that sensory impairments could hinder participation (Backhouse et al., 2016). Participants were offered the opportunity to be supported by a person or people in an environment of their choosing (Mckillop and Wilkinson, 2004). Care staff participation and inadvertent domination were managed carefully in recognition of the potential influence of power in relationships (Downs et al., 2001, Martin and Younger, 2000a). Questions were reworded and repeated as necessary.

Table 10: Organisation of Focus Groups in Each Care Home

Focus group organisation	
Treetops	I organised the focus groups myself and identified the times that had minimal impact on the staff and residents (during morning or afternoon activity sessions). I then checked the duty rota and organised my visits to coincide with participants duties. I asked the care staff the week before the focus group if they would be happy to speak to me on the given date and they always agreed on the proviso that they their workload allowed them to attend. I tried to only take one member of staff from each unit at any given time and where possible arranged the focus groups to be in a quiet environment away from distractions.
Eden Valley	The clinical lead organised the focus groups with me and, where possible organised the duty rota around the groups. The clinical lead added the time and date of the focus groups to the staff participants rotas. The staff were then (mostly) given protected time away from their units to attend the focus groups. The clinical lead also organised a quiet room for all the focus groups. The only exception was the resident focus group which I facilitated based entirely upon the residents' requirements.

Data analysis

Arguably the most important aspect of analysis in AI is transparency, so that any contributions to theories can be evidenced (Reed, 2006). Reed proposes that AI findings inform both broad theoretical issues relevant for practice, and micro-theories, such as the way that multiple senses were used to facilitate decision-making interactions between a person living with dementia and their staff or family care partner in these care homes.

The way that data were generated (and analysed) with and by the participants themselves affected the analytic process. Participants developed the dream ideas into designs and eventually destiny. They therefore undertook much of the analysis themselves through the discussion, debate and exploration of why something was seen to work well. This is a usual approach in AI (see for example, Clouder and King, 2015, Mishra and Bhatnagar, 2012, Whitney and Trosten-Bloom, 2010). I documented and interpreted the multiple ideas being generated as they were processed and/or discarded by the participants. For example, multiple stories about food related decisions generated several dream ideas about how to support food related decision-making. These ideas were grouped by participants to summarise their focus and approach (for example, using pictures or gestures and limiting or extending choices).

I transcribed 33 of the 39 audio recordings of the interviews and focus groups myself and listened to, and checked, the six that were outsourced for transcription. Transcription is considered an important first level of analysis (Woolf and Silver, 2017) to build familiarisation with the data. Ideas generated in earlier stages of the 4D process where verified with participants in the interviews and focus groups in the later stages of the 4D process. Participants were asked if; a) I had understood the idea correctly and b) if they still believed that they would like to take the idea forward (or the idea had been taken forward). At each step of the process the ideas were anonymized, and participants thoughts and feedback were incorporated into the ongoing analysis. This type of respondent validation of transcripts and other data is advocated to promote validity (Johnson, 1997).

Content analysis was used to systematically code the data from the 4D cycle. It is recognised as useful for analysing the complexities of nursing research and studies conducted in an area where not much is known (Elo and Kyngäs, 2008, Vaismoradi et al., 2013). Content analysis offers the ability to quantify the data (counting the number and types of ideas and how they were proceeded) whilst also analysing the qualitative aspects of the data (Kitto et al., 2008, Vaismoradi et al., 2013). For example, identifying the frequency of dream ideas and how they presented across participant groups may have been indicators of levels of interest or organisational context.

Analytic strategies

To organise, map, categorise, interpret and check the data the analytic approach drew on the five level Qualitative Data Analysis (QDA) Framework (Woolf and Silver, 2017) (Table 11). The themes identified from the systematic review and observations in the discovery and dream stage were supplemented by inductive methods to build theory from the data collected.

I used NVivo as a tool to organise and manage the data; to aid analysis and to demonstrate, develop and test relationships between layers in the data (Woolf and Silver, 2017). I created each care home as a standalone category and each participant as a case. I then associated individual participants to their respective care homes and added their demographic data to them as attribute values.

The observation field notes and focus group and interview transcription sources were classified by care home and the appropriate stage of the AI process (discover and dream, design or destiny). Each source classification was then allocated attribute values. For example, observation field notes were given attribute values of pre or post innovation, and AI stages were given attribute values such as interview, focus group, hospitalised or incomplete, to reflect each stage of the process. Any participant interviews or focus groups that included more than one stage in the 4D cycle were attributed to each stage that they included. This approach to analysis meant it was possible to track how ideas were progressed and what the influencing factors might be. The ideas from the dream stage, and how they developed were compared within and across participant groups and homes. For example, if a group of staff thought that pictures could be used to improve shared everyday decision-making, did other care staff and/or residents and/or family care partners identify similar ideas, and in which decision-making fields.

Analysis also sought to determine interactions and/or conditions present that led to the uptake and development, or dismissal, of a dream idea. Bazeley's (2009) three-step approach (describe, compare, relate) was used to interrogate the data. For example, did discovery stories in focus groups lead to different dream ideas than individual interviews? Were multiple accounts or consequential stories more common in focus groups; and did this have an impact on the idea's journey through the 4D cycle?

Table 11: Five Level QDA Framework (Woolf and Silver, 2017) Application

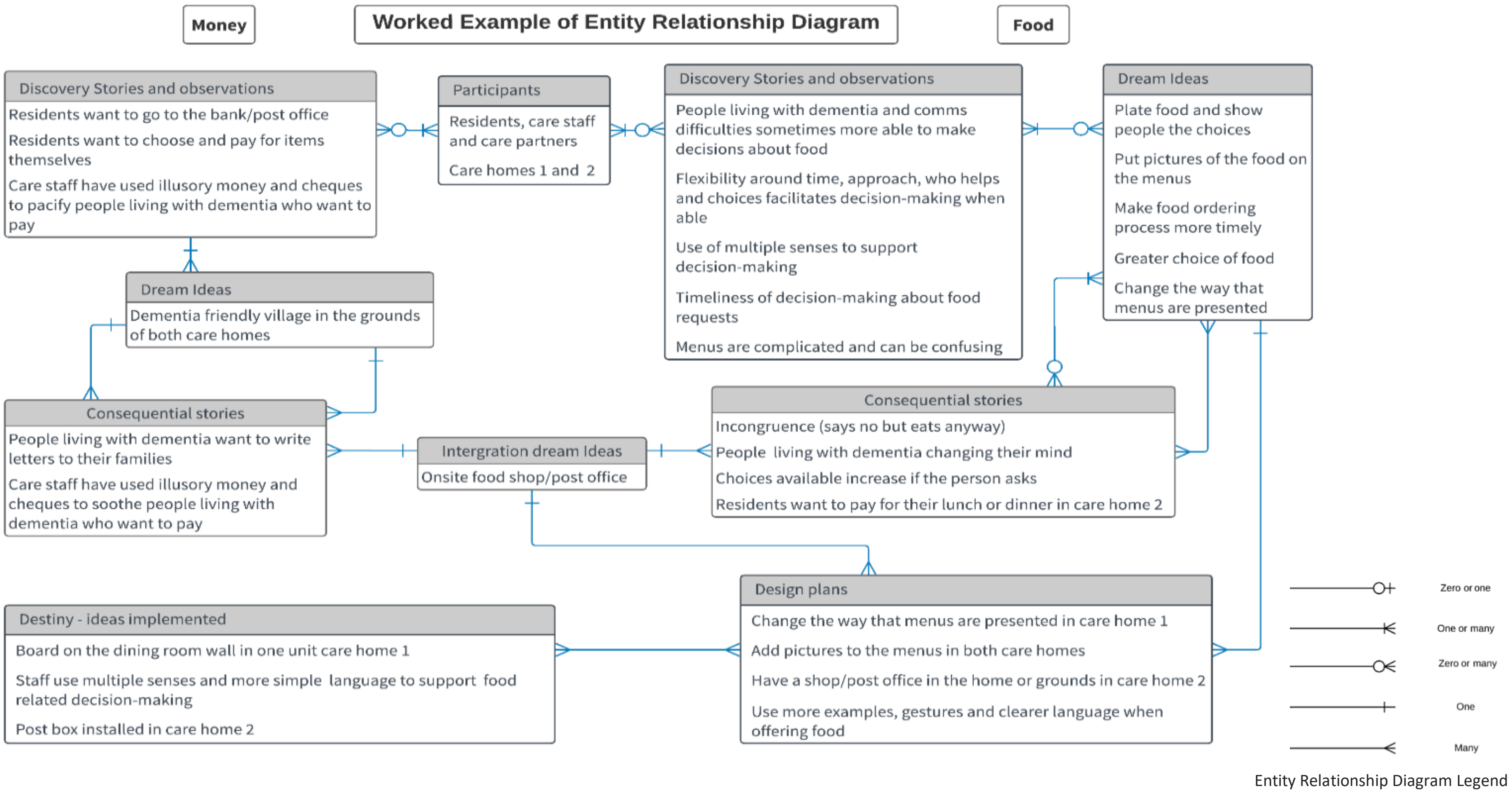
Five Level QDA Framework Application	
Integrate	The outcomes from the systematic review were imported into NVivo so that existing knowledge could be easily integrated and compared with my data. Field notes from observations and verbatim transcriptions of interviews and focus groups were uploaded into the NVivo computer software package to be organised coded and interrogated. Demographic data, and supplementary quantitative data (DCDS and QOL-AD) were uploaded to further inform AI data.
Organise	Data were mapped by care home and individual ('cases' or files were created to contain data). Data sources were classified (by care home, and by stages of the AI process). Demographics were uploaded and attached to each case The conceptualisation of coding was created based on outcomes of the systematic review and structures used throughout the data collection process (see 'reflect' below).
Explore	Data were transcribed verbatim giving an opportunity for familiarisation with the data and surface level analysis. Content analysis was undertaken through line by line coding Decision-making themes were a) taken from existing literature (identified though the systematic review) and b) developed from the data collected.
Reflect	The AI 4D cycle (Figure 5) created a clear structure for the surface level analysis. The DMI checklist initially provided a structure for the observations and then structured using the observation schedule. Interview and focus group questions provided structure for the abductive content analysis. Types or fields of decision-making were coded as nodes and examples were counted. This data was then further analysed to identify if frequency of examples reflected frequency of decisions or something else, such as repetition. Levels of decision-making were identified within the spectrum of decision-making* (Smebye et al., 2012), and enabling factors were noted and categorised as they were identified. Each dream idea was mapped against the decision type or field and how that decision was shared or facilitated.
Interrogate	Participants and related data were described and compared between and across participants, groups and homes, and patterns of association were noted and explored using Bazeley's (2009) three-step approach Ideas identified in the dream stage were coded and then repeats, and developments of that idea were mapped and counted throughout each stage of the 4D AI cycle. Anomalies were noted and interrogated further.

**Smebye and colleagues (2012) spectrum of decision-making was used to map the extent of participation in decisions by people living with dementia. Smebye and colleagues (2012) extended Thompson's (2007) taxonomy of patient involvement to include people living with dementia.*

Many AI studies appear to complete their analysis at a surface level, describing implementation and evaluation of the 4D cycle but providing little detail of data analysis (Bushe, 2011). Grant and Humphries (2006) go as far as to suggest that AI discourages critical analysis beyond description. They argue that a more critical evaluation of the complexities in the process could help to expose and address embedded power imbalances within organisations. Clouder and King (2015) also suggest the need for a greater degree of reflexivity in the analysis of AI to promote the trustworthiness of the findings; a need identified in care home research more generally (Luff et al., 2015).

Content analysis was used to identify examples of everyday decisions made and shared by people living with dementia and communication difficulties captured in the care homes during observations, interviews and focus groups (for example the decision of what to eat for dinner was included in the theme ‘food and drink’). Using the ‘describe, compare, relate’ process, the key decisions were then explored in relation to enabling factors of shared decision-making practices (e.g. people, routines or environmental factors) and participants (who shared in the decision).

An entity relationship diagram was developed (Figure 7) to analyse how data from multiple observations and stories were interwoven as the AI progressed. The purpose was to understand whether observations, stories and ideas came from single or multiple sources and relationships in the data. The diagram was created on paper and grew as additional relationships in the data were identified. Figure 7 represents one small section of the diagram as an illustrative example. It demonstrates how stories and observations about food inter-linked with stories about people wanting to access and spend money. Observations and stories led to dream ideas (and consequential stories) within and beyond each original entity (in this case food). Other relationships in the data were identified between food and; physical activity, who to spend time with, going out and where to go in the home or grounds. Other relationships identified through this process can be seen in Table 23 where the decision-making fields are mapped against participant ideas and enabling factors.



Worked Example of Entity Relationship Diagram

Money

Discovery Stories and observations
- Residents want to go to the bank/post office
- Residents want to choose and pay for items themselves
- Care staff have used illusory money and cheques to pacify people living with dementia who want to pay

Participants
- Residents, care staff and care partners
- Care homes 1 and 2

Dream Ideas
- Dementia friendly village in the grounds of both care homes

Consequential stories
- People living with dementia want to write letters to their families
- Care staff have used illusory money and cheques to soothe people living with dementia who want to pay

Intergration dream Ideas
- Onsite food shop/post office

Destiny - ideas implemented
- Board on the dining room wall in one unit care home 1
- Staff use multiple senses and more simple language to support food related decision-making
- Post box installed in care home 2

Food

Discovery Stories and observations
- People living with dementia and comms difficulties sometimes more able to make decisions about food
- Flexibility around time, approach, who helps and choices facilitates decision-making when able
- Use of multiple senses to support decision-making
- Timeliness of decision-making about food requests
- Menus are complicated and can be confusing

Dream Ideas
- Plate food and show people the choices
- Put pictures of the food on the menus
- Make food ordering process more timely
- Greater choice of food
- Change the way that menus are presented

Consequential stories
- Incongruence (says no but eats anyway)
- People living with dementia changing their mind
- Choices available increase if the person asks
- Residents want to pay for their lunch or dinner in care home 2

Design plans
- Change the way that menus are presented in care home 1
- Add pictures to the menus in both care homes
- Have a shop/post office in the home or grounds in care home 2
- Use more examples, gestures and clearer language when offering food

Figure 7: Example of Entity Relationship Analysis Process

The concept of entity relationships was useful to understand the complex nature of everyday decisions that were shared by people living with dementia and communication difficulties with their staff and family care partners, including how they were described, influenced and understood.

Credibility and Trustworthiness

Validity, reliability and generalisability of results are considered to be quality markers and evidence of research rigour (Johnson, 1997, Ritchie et al., 2013, Silverman, 2013). Establishing the credibility and validity of the findings is tied into the research approach in AI as previous interview and focus group data is fed back to and checked by the participants throughout the study. The multi-method approach to data collection enabled me to corroborate findings and the repetitive nature of the interviews and focus groups meant that I could check understanding with participants (Clouder and King, 2015, Reed, 2006, Trajkovski et al., 2013). Particular attention was paid to accessing the perspectives of people that would not normally be included in research studies, such as people living with dementia and communication difficulties (Hubbard et al., 2003, Mckillop and Wilkinson, 2004).

Reliability in qualitative research is predominantly discussed in terms of low-inference descriptors; ensuring that data are recorded in the most ‘concrete’ terms possible (Johnson, 1997, Seale, 1999, Silverman, 2013). To promote a clear audit trail and the opportunity to revisit the data I made real time notes of observations and digitally audio recorded the interviews and focus groups. The recordings were transcribed verbatim to minimise my interpretation in reporting the data (Johnson, 1997, Seale, 1999, Silverman, 2013). I also maintained reflective diaries throughout my data collection.

Data saturation is widely cited as a useful quality assurance measure, however there is rarely a clear description of how it was achieved in Appreciative Inquiry and there is always potential for new coding as researchers become more familiar with their data (Marshall et al., 2013, Mason, 2010). To reflect the transparency advocated by Reed (2006) the nature of the process meant that as ideas were honed and developed by the participants, new idea generation was organically limited by the 4D cycle and the agreed timeframes. The process focused on adequacy and comprehensiveness of the data collection in relation to the AI cycle over data saturation.

Public and Patient Involvement (PPI)

Increasing PPI in research is an established policy in the UK (Department of Health, 2006). The National Institute of Health Research (NIHR) calls for people to be active partners in research by, for example, advising on research projects. Guidance has been developed to support researchers to effectively involve care home residents and their care partners in research (Twiddy et al., 2013). However, inclusion of care-home residents in the research process continues to be limited and few studies have successfully involved older care-home residents in the research process (Backhouse et al., 2016). A systematic review by Backhouse and colleagues (2016) identified participatory action research such as AI, as one way of successfully involving focusing on actual or potential interventions, and as consultants on larger-scale studies (8+ care homes). However, three levels of PPI are recognised (Mcmurdo et al., 2011); consultation, collaboration and user control. This study has been designed to employ all three levels.

Consultation

In consultation, the systematic review, research questions and study design were presented to the members of the University of Hertfordshire Public Involvement in Research Group (UHPiRG), some of whom have experience of caring for family members with dementia who lived in care homes. The UHPiRG members were positive about the approaches selected. They suggested maximising diversity by recruiting homes from a range of CQC ratings (from requires improvement to outstanding). They recognised, however, the problems of recruiting care homes who were under additional pressure to address regulatory concerns. We also discussed the challenges of representing socio-economic diversity and agreed my choice to approach homes that reflected a combination of privately and publicly funded care in rural and urban locations. I had not considered approaching homes from different CQC ratings and as a result of PPI engagement I approached a care home from each of the four CQC ratings. Study progress and outcomes were shared with the group in line with best practice recommendations (Mathie et al., 2018).

Collaboration

The principles of AI promote a collaborative process. Respecting the individuals who participated in the study, and positioning everyone as capable of having useful input aided the process and corroborated evidence that people living with dementia are able to participate in the decisions about their life and care (Daly et al., 2018). Without the voice of the user or intended beneficiary of the research it lacks validity (Nolan, 2007).

User control

In this study participants in the care homes were included as co-researchers, shaping the design of the interventions. Throughout the study, data was fed back to participants to verify understanding and to enable and empower them to decide which ideas to progress to the next stage of the AI cycle.

Unlike previous studies with care homes specialising in dementia care where residents had minimal involvement (Aveyard and Davies, 2006), this study allowed individuals to be involved in the way that best suited them. The inclusion of participants living with dementia and communication difficulties and the people that they share their everyday decisions with enabled their voices to be heard in the process and ensured that study outcomes met their needs and wishes.

Multiple data collection methods maximised access to the stories and ideas of all the participants and enhanced inclusion of as many different perspectives and ‘voices’ as possible (Hubbard et al., 2003). Learning from previous research involving older care-home residents as PPI members helped to improve the effectiveness of how this marginalised group were able to play an active role in this study (Aveyard and Davies, 2006, Backhouse et al., 2016, Hewitt et al., 2013, Shura et al., 2011). Each relationship that the researcher entered into was created and developed with respect for the potential authentic contribution that the person could bring to the AI process.

Chapter summary

This chapter has described the Phase 2 study design and identified how consent processes have been employed to overcome ethical challenges. Care home and participant recruitment have been discussed and the selected methodology and methods have been justified. The use of analytic strategies that have included participants have been acknowledged and I have promoted transparency by acknowledging alterations made to the AI 4D cycle to include participants with cognitive and communicative difficulties and have explained the importance of PPI in this study.

Chapter 4 - Discovery Stage Findings

Introduction

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

The chapter includes;

- a description of the study settings and participants,
- fields of everyday decision-making that were identified as being made *with, by* and *for* people living with dementia and communication difficulties,
- levels of involvement in everyday decision-making,
- key factors identified as enabling decision-making involvement.

Some data are presented in tables, with example excerpts from observational field notes and interview transcriptions aiming to represent the voices of the participants. Findings from the discovery stage of the 4D cycle form the basis for the intervention stages of the study (dream, design and destiny) presented in the next chapter.

Setting

Two nursing care homes participated in the study. The care homes were comparable in their size and the type of care that they deliver. Both the care homes are recognised by the regulator as providing exceptional standards of care. Dementia care units in both care homes were purpose built and had what would typically be expected of such physical environments including; clear, clean, spacious rooms that incorporated positive distractions, a range of furniture and (for most) freely accessible, secure outside spaces. In addition to the material aspects of the units, routines, particularly in the high needs' dementia care units, were developed to incorporate the preferences of multiple individual residents. For example, care staff provided breakfast throughout the day and residents could take it wherever they pleased. This use of adjustments to routines to maximise residents' comfort and minimise distress appeared to be common practice across both homes throughout my observations. Characteristics of each home can be seen in Table 12 and a more detailed description of each care home in Appendix 7.

I had a pre-existing relationship with the manager and clinical lead in one of the care homes, and professional links with the other home (although I had not met the manager or clinical lead in person). I considered that my previous experience working in and with care homes was pivotal to the ease with which I was able to access the homes and central to developing relationships with staff in both homes. This was partially confirmed by a conversation with the clinical lead in one of the care homes who reflected that they carefully considered the studies that they were asked to participate in. I was interested to understand if, in this case, it was the researcher or project that impacted on her decision, as a gatekeeper, to facilitate access. She told me that, for her, it was a combination of factors. The focus of the study needed to be aligned with the culture, ethos and priorities of the care home and its stakeholders, but also that the researcher needed to be able to build and maintain a relationship with the everyone in the care home. This supports research by Holloway et al. (2010) who argue that the researchers relationship with the gatekeeper is vital to participant access and data collection.

Table 12: Characteristics of Participating Care Homes.

Characteristics of Participating Care Homes		
Care Home	**'Treetops'**	**'Eden Valley'**
CQC registration	Dementia care Nursing	Dementia care Nursing
Ownership	National not for profit organisation	National private organisation
Funding	Predominantly Local Authority	Predominantly private
Location	Southern England - Urban	Southern England - Urban
Size: maximum number of residents	90 Beds in 6 units	90 Beds in 6 units
Dementia care units	2 units (30 beds)	3 units (45 beds)

There was a high proportion of people living with a dementia diagnosis (or symptoms consistent with a diagnosis of dementia) on all the nursing units in both care homes. At the time of recruitment, the clinical lead in Eden Valley estimated that 80 per cent of the residents were living with a dementia, and the manager in Treetops estimated between 75 per cent and 80 per cent of the residents were living with a dementia. These estimates are representative of the national figures (Cousins et al., 2016) and suggest that on average between five and ten residents were living with dementia on each nursing care unit.

Study Population

Forty-three people participated in the study across the two care homes. The breakdown of participants from each care home are presented in Table 13. Two staff left Eden Valley during the study and their replacements were recruited into the study and included in the AI process. This meant that a total of sixteen care staff were recruited from Eden Valley.

Table 13: Gender Breakdown of Participants

Study Participants by gender								
Participants	**Total**			**Treetops**			**Eden Valley**	
Gender	**M**	**F**		**M**	**F**		**M**	**F**
Residents	4	11		1	7		3	4
Care Staff	5	19		3	5		2	14
Care Partners	1	3		1	2		0	1
Total	**10**	**33**		**5**	**14**		**5**	**19**

A male resident participant living with advanced dementia, recruited from Eden Valley was not interviewed. He was either sleeping or unable to participate due to our inability to establish an effective way of communicating. This was despite several attempts using a variety of communication support tools and accessing staff and family care partners assistance.

Most participants (n = 31) were able to consent for interviews and focus groups, including all staff and family care partners and four residents. Nine additional residents used process consent and three participants with more advanced dementia and communication difficulties participated through the consultee process. One of these participants used to work in research, and his consultee (his wife), was adamant that he would have wanted to participate if he were able to consent. She also participated in the study, agreeing to all aspects of the consent form but the voice recording. I had not anticipated this and was unsure of how to proceed in an ethical and morally sensitive way. I discussed this with her and we continued with their joint interview. I took detailed notes of their responses (with consent). This worked well, however it did mean that I had one interview that I could not revisit for clarification. One interview was cut short because I was not sure that the resident fully understood what I was asking of her. I stayed and chatted with her after I had ended the interview to demonstrate to her that she was still valued as part of the research process (Mckillop and Wilkinson, 2004).

Researchers should be open and reflexive about their ethical processes and decisions during fieldwork (Luff et al., 2015). I found care partners particularly hard to recruit and this may have influenced my decision to proceed, although on reflection I still feel that I made the right decision.

Demographic data

The fifteen residents’ ages ranged from 60 years to 97 years (Table 14). The care partners’ ages ranged from 72 years to 85 years with one care partner choosing not to disclose her age (Table 15). Residents and care partners all described themselves as white British.

Treetops care staff were aged from 27 to 50 years and one carer chose not to state her age. Eden Valley care staff ages ranged from 23 to 59 years. Most of the Eden Valley staff described themselves as white British (n=11). The other care staff at Eden Valley described themselves as Caribbean (n=1), white Polish (n=1), Asian (n=1), and mixed Irish/Arab (n=1). Treetops staff described their ethnicity as white British (n=3), Polish (n=1), Romanian (n=2), Spanish (n=1) and Pakistani (n=1).

Table 14: Resident Demographics

Resident Demographics				
Care Home	**Gender**	**Age**	**Unit**	**Length of time resident**
Treetops	M	74	Dementia	13 months
Treetops	F	84	Dementia	13 months
Treetops	F	85	Dementia	2 years
Treetops	F	86	Dementia	2 months
Treetops	F	86	Nursing	5 years
Treetops	F	90	Nursing	2 years
Treetops	F	94	Nursing	18 months
Treetops	F	97	Nursing	4 months
Eden Valley	F	69	Nursing	7 months
Eden Valley	M	75	Dementia	4 months
Eden Valley	M	85	Nursing	4 months
Eden Valley	F	85	Nursing	14 months
Eden Valley	F	86	Nursing	5 months
Eden Valley	M	94	Nursing	4 ½ years
Eden Valley	F	95	Dementia	2 years

Treetops care staff were aged from 27 to 50 years and one carer chose not to state her age. Eden Valley care staff ages ranged from 23 to 59 years. Most of the Eden

Valley staff described themselves as white British (n=11). The other care staff at Eden Valley described themselves as Caribbean (n=1), white Polish (n=1), Asian (n=1), and mixed Irish/Arab (n=1). Treetops staff described their ethnicity as white British (n=3), Polish (n=1), Romanian (n=2), Spanish (n=1) and Pakistani (n=1).

Table 15: Care Partner Demographics

Care Partner Demographics				
Care Home	**Gender**	**Age**	**Relationship to resident**	**Length of relationship**
Treetops	F	75	Wife	52 years
Treetops	F	Not stated	Daughter	Not stated
Treetops	M	85	Husband	73 years
Eden Valley	F	72	Wife	50 years

Staff participants worked in a range of roles and designations. Most Eden Valley staff participants were team leaders (n = 12), whilst most Treetops staff participants referred to themselves as care workers (n = 6). One participant from each home was a qualified Registered Nurse. Eight staff identified themselves as working predominantly on dementia care units and all care staff had experience of working in dementia care. Two members of staff (one from each home) covered the whole care home; one as an activity coordinator and the other as a ‘floating’ care worker and part-time cook. A greater proportion of male staff participated from Treetops (n=3) than Eden Valley (n=2). Overall, of the twenty-four staff participants, nineteen (79 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 (Skills for Care, 2015).

Treetops care staff participants had worked there between 1 and 9 years with a median of 36 months. All had previous care experience; one in children’s Learning Disability services and the remaining seven in older peoples’ care. Eden Valley care staff had worked in the care home for between 9 months and 5 years 9 months with a median of 28 months. Eleven of the sixteen staff who participated (69 per cent), also had 3 - 25 years previous care experience. During the discovery process, eight care staff participants disclosed that they were currently caring (or had recently cared) for a close relative living with dementia.

Dementia and communication difficulties

Most of the fifteen participating residents (n=11, 73 per cent) had a diagnosed dementia; seven Alzheimer's Disease (AD), two vascular dementia (VaD), one alcohol related dementia (ARD) and one unspecified. The four residents without a dementia diagnosis displayed symptoms that the care staff perceived as consistent with dementia (that is, confused speech, memory impairment and/or personality changes). These four residents all had either diabetes or vascular disease, which have been linked with dementia as common comorbidities (Bunn et al., 2014). Nine residents, including the four people without a formal diagnosis, lived in nursing (non-dementia care) units, highlighting the importance of all care staff now understanding dementia care strategies. The remaining six residents lived in high needs dementia units.

Care staff were aware of, and able to explain the Mental Capacity Act (2005) and how it affected their residents and themselves. However, unless a resident had a Deprivation of Liberty Safeguard (2007) (DoLS) order in place they rarely completed mental capacity assessments for everyday decisions; instead using principle one of the MCA (2005) – presumption of capacity unless they had reason to believe otherwise.

The Dementia Communication Difficulties Scale (Murphy et al., 2007) (DCDS) proposes the following stages of dementia based on communication scores:

- DCDS ratings between 0 and 10.5 = early stage
- DCDS ratings between 11 and 19.5 = moderate stage
- DCDS rating between 20 and 39 = late stage

The DCDS scores are presented in Table 16. Two people living on nursing units had severe verbal communication impairments related to other physiological conditions (such as stroke), and this distorted their DCDS scores, wrongly suggesting they were living with late stage dementia. Other residents who had been diagnosed within the preceding 12 months had a moderate score. By focusing entirely on verbal communication, the DCDS did not account for other communication impairments. For example, visual impairment was the most common communication difficulty that resident participants identified, with all but one saying that it affected their ability to communicate effectively. The next most common communication difficulty was dysphasia or aphasia (n=8). Hearing impairment was referenced by seven residents as a barrier to communication and one resident spoke about breathing difficulties significantly affecting his ability to communicate. This was classified as ‘other’. Thirteen of the resident participants (87 per cent) had multiple communication impairments.

Two of the participants living with dementia were aphasic. One of these participants. sat quietly and appeared to be listening at times and sleeping at other times. Her care partner talked to us both throughout and looked to her for confirmation when answering some of the questions. At these points she would sometimes smile and/or squeeze his hand. The second person appeared to listen attentively and used picture cards, non-verbal signs and support from her key worker to participate in the interview.

A further participant living with dementia and severe dysphasia participated in an interview with his care partner. He answered some questions, although his words were not coherent and did not appear to be related to the questions. He looked at the communication cards, that I had taken with me (see Figure 8) and spent considerable time sorting through them (07 minutes). He selected four cards and put the rest in a neat pile on the table. I asked if he would like to show me that cards and he showed me three; happy, listen to the radio and glasses. He then left the room independently and took his glasses and the four cards to a nurse sitting at the nurses’ station. I left the cards on the unit in case the residents or care staff wanted to use them further.

Figure 8: Communication Cards Offered as Support for Interview Participants

Care staff demonstrated a level of awareness about the impact of their own, and others, emotions on the people in their care. For example, after two residents died in a high needs' dementia care unit in Eden Valley over the Christmas period, a member of staff discussed it in a focus group.

> *CSF 45 – I think when somebody dies it changes the whole unit for a little while … your residents know … it's like a sad feeling … The unit just goes quiet for a couple days it's quite a, a flat (tails off and looks down) … I've always said [on the unit], you don't show your feelings. You don't come in in a bad mood and let them see you in a bad mood, you've got to be positive, laughing and joking because… they will pick up on it and it will make them play up a little bit, if they know you're not happy … It's like when somebody dies, you've still got to be smiling. You can't let them see it's affected you. Go in the toilet and cry and wash your face and come back out. It's – you can't let them see. It's not their fault, you know?...*

Six of the care staff (25 per cent) had English as a second language. I did not observe miscommunication between the care staff and residents living with dementia resulting from language differences, although there was an incident in an interview where a member of staff misinterpreted me and was shocked when I clarified her answer.

> *CSFN31: …I offered for her to go to the toilet, if she would like to sit in the commode – on the commode – sorry. And she say yes so it was easy after that. Because if …*

> *she would like to go to their commode and sit down over there and she can see something inside her pad, she know what's going on…*
> *RD: So you used a visual cue as well?*
> *CSFN31: (looks shocked) not the visual cue. No. No. Not like that. She went to the toilet and she saw that she was dirty. Because I only suggest to her "come on let's go to the toilet".*

Quality of Life of People Living with Dementia

The Quality of Life in Alzheimer's Disease (QOL-AD) (Logsdon et al., 1999) instructions for interviewers were followed where possible. However, it was necessary to make the modifications detailed below. In an early interview, a participant who was identified by staff as living with symptoms of dementia, but did not have a formal diagnosis, became distressed, indicating that it was because the form had the words 'Alzheimer's' and 'dementia' on it (Appendix 8). The participant did not complete the form. Similarly, a care partner started to complete the form and then stopped because she was 'bothered' by the word 'Alzheimer's'. Following these incidents, participants and their family care partners were asked the questions but not given the form to complete themselves. In addition, instructions to interview the subject alone were also not followed when participants had asked to be interviewed with a staff member or family care partner. The DCDS and QOL-AD scores are presented in Table 16 below.

Almost half of the participants living with dementia (n=7) either chose not to complete the QOL-AD or were unable to do so: Five lived in Eden Valley care home. All three participants who were unable to complete the QOL-AD lived on dementia care units and had a DCDS score of higher than 34.

Two spousal care partners started to complete the forms but declined to finish because they were uncomfortable answering the question about marriage. They were not asked to answer any further questions. Quality of life scores between the person living with dementia and their informant varied from -10 to +11. There were four examples of people living with dementia and communication difficulties scoring their own quality of life higher than their informant and two scores that were equal. There was only one episode of a care worker scoring the person living with dementia as considerably higher than the person had scored themselves. The care worker was not the participants key worker or named nurse.

The QOL-AD was due to be repeated during the destiny stage of the 4D cycle but due to the distress that it had caused some participants and the resulting difficulties in using the tool as it was intended, the QOL-AD score was not repeated.

Table 16: Characteristics of Participants Living with Dementia

Characteristics of Participants Living with Dementia						
Participant Code	**Dementia diagnosis**	**DCDS score**	**Self QOL-AD score**	**informant QOL-AD score**	**Role of informant**	**QOL-AD score Variance**
MR10	AD	34	unable	29	Wife	n/a
FR21	None	16	36	32	Daughter	-4
FR20	unspecified	14	36	28	Key worker	-8
FR26	AD	15	36	26	Care worker	-10
FR06	None	38	incomplete	22	Key worker	n/a
MR46	ARD	9	32	32	Key worker	0
FR350	None	3	38.5	36	Key worker	-2.5
FR28	AD	9	34	34	Key worker	0
FR25	VaD	14	29	30	Care worker	+1
FR021	AD	4	declined	45	Named nurse	n/a
FR022	AD	17	incomplete	35	Care worker	n/a
FR023	85	8	33	44	Care worker	+11
FR16	VaD	37	unable	incomplete	Husband	n/a
MR05	AD	37	unable	incomplete	Wife	n/a
MR47	None	37	declined	27	Key worker	n/a

DCDS – Dementia Communication Difficulties Scale, QOL-AD – Quality of Life in Alzheimer's Disease, AD – Alzheimer's Disease, VaD – vascular dementia, ARD – alcohol related dementia. QOL-AD score Variance - A minus number represents the care partner scoring the persons quality of life lower than they scored it themselves. A positive score means that the person living with dementia scored their quality of life higher than their care partner.

Discovery stage observations, interviews and focus groups

Observations

There were six observations lasting three hours in each home in the discovery stage of the 4D cycle (Table 17). Observations took place between the hours of 7.45 am and 9 pm.

Focus Groups and Interviews

All interviews and focus groups were conducted in the care homes. There was a total of 13 focus groups across both homes throughout the 4D cycle (Table 17). Each group contained between 3 and 8 participants. The focus groups were audio recorded and lasted between 46 and 84 minutes.

Four of the 26 interviews included 2 participants. These joint interviews were to accommodate residents and/or care partners requesting to be interviewed together. Interviews ran between 8 and 78 minutes and all (bar one) were audio recorded.

Table 17: Data Collection Methods

Data Collection Methods		
Data collection method	**Treetops**	**Eden Valley**
Discovery observations	18 hours	18 hours
Discovery interviews (n=)	16	4
Discovery focus groups (n=)	1	7

Some participants (n= 11) completed the AI process in a single interview or focus group at their own request. This included nine people living with dementia and two of the family care partners. Where participants only attended a single interview or focus group they were recorded and analysed against each stage of the AI process that was completed. It did mean, however, that for these participants there was no opportunity for reflection between stages or time for implementation or change in practice. This is discussed further in the 'Strengths and Limitations' section of the Chapter 6 (Discussion).

Complete 4D Cycles

Fourteen people living with dementia and communication difficulties (80 per cent), 21 care staff (88 per cent), and three family care partners (75 per cent), completed the 4D cycle.

Incomplete 4D Cycles

Six people were unable to complete the 4D cycle, three in Treetops and three in Eden Valley. In Treetops one of the residents died and another was hospitalised. One care staff participant was unavailable for the final interview due to work commitments. In Eden Valley two care staff left the home (but were replaced). One care partner was hospitalised and so was unable to complete the final interview. In addition, one participant living with dementia in Eden Valley was recruited but did not commence or complete any interviews.

Fields of everyday decision-making

The first research question was to understand the types (or fields) of everyday decisions that people living with dementia make and share in the care homes. The discovery stage observations and stories helped to identify these common decisions. Decisions were grouped into 20 different categories. These categories and the frequency with which they arose can be seen in Table 18. An example is provided for each decision field to demonstrate how the decisions were played out or portrayed by the participants.

Care staff provided multiple positive stories about residents participating in decisions and choices about their care. Some stories were common amongst care staff; a participant would start telling a story and others would join in, recognising the person or decision-making episode that the story was about. Some of the stories were simple statements, made in passing, involving an aspect of resident decision-making or choice:

> *"I'm down here, but I've still got to go upstairs and give FR350 her shower cos she won't let anyone else do her shower…see I like that, cos that's her choice." CSF21 (treetops)*

Despite working on another unit, the participant above negotiated time to go and shower a resident on her usual unit. Other stories were described in more detail and referred to by the same care worker several times emphasising the importance of giving people choices. The excerpt below is from a story that a care worker repeated several times:

> *"… I offered her tomato soup or vegetable soup or another soup and she goes she wanted tomato soup and her daughter went crazy at me. She said "why are you giving my mum tomato soup? She's never had that in her life" I go "she asked for it, and I'm not gonna not give it to her" and she goes "she won't eat it – you're wasting it" and I go "nah, she said she wants it and I'm gonna try…if she doesn't like it, it's not the end of the world". I gave it to her and … she ate the whole bowl! The tomato soup! She goes "this is the most beautiful taste I have ever had in my life!" and I go "there you go…even if they haven't had it in the past…we give our residents choices, we don't stick to the same thing all the time. We don't have a set routine when they all have to be up at 8 o'clock" and I goes "It's different here" … and her daughter …*

> *goes “I’m sorry that I ever doubted you”. I go “it’s not about doubting me… I know she’s got a dementia … but sometimes, you know, the taste buds changes and people like different things”. CSF22 (treetops)*

Most of the stories used examples about food and drink. This was also the field of decision making most commonly observed, along with those relating to organised activities. Decisions relating to clothing, getting up, going to bed, personal care and care of personal space and objects were not witnessed during observations despite participants regularly referring to them in interviews and focus groups. This may be because observations were only undertaken in communal spaces.

The examples in Table 18 also begin to demonstrate how the spectrum of shared everyday decision-making was represented and understood by participants. This extends from the resident taking control of who to go to for help to examples where the staff clearly held the power, even when they are responding to the residents’ needs or wishes. For example, the resident joking about having his wheelchair ‘clamped’ or the staff ‘letting’ people lie in. This is discussed further under Spectrum of decision making.

Table 18: Decision-Making Fields with Frequency and Examples

Decision-Making Fields with Frequency of Decision and Examples				
Decision-making Fields	Observed	Interview stories	Focus group stories	Examples
Food and Drink	5	70	47	CSF1 to FR1 – 'Do you want a drink? It's blackcurrant' CSF 1 bends down to talk to FR1 face-to-face. FR1 'Yes. Do I like blackcurrant?' CSF1 shows her the juice. 'It's a funny colour. Yes, I like it'. CSF1 pours her a drink and helps her to pick it up.
Clothing	0	24	4	*With FR [name] for example, she always wants to pick her own clothes. She would sometimes make me take out her whole wardrobe. Sometimes there is not time, so I will pick a few clothes out for her to choose. She will point at them because her speech isn't good. I will take trousers or skirt and she will pick what she wants to wear. (CSM6)*
Organised activities	5	22	17	FR4 to ACF1 'what are we going to do?' 'Do whatever you like. Clap or join in or just listen'. 'But what is it?' 'Exercises.' 'Lovely' starts tapping knees as music starts.
Going to bed	0	15	6	CSF to FR 'would you like a hot drink [name]?' 'No. thank you dear. Maybe in bed. Maybe I should go to bed? Can I go to bed now?' 'If you want to?' 'Yes please, and I will have a hot drink in bed'. 'Of course, here let me help you into your wheelchair and I will take you up to your room' 'Yes, thank you dear.'
Personal care	1	18	25	*I went to one of the rooms and I found my resident with a terrible smell…so I suggest to her "oh, would you like to have a little wash?" because she was dirty…and she refused at the beginning. I say, "if you don't mind…" and I try to, try to, explain the benefits about a little wash. And after few minutes, she said "yes", and I said to her "oh, you will feel better, honestly" and she said yes. I tried to clean her properly – her bottom quite good – and when she was sitting again, she said to me (leans in and touches my arm) "oh, thank you very much" (CSFN31)*
Getting up	0	10	8	*… some have personal care then go through to the dining room cos that's their choice, we have others that eat in bed and they might be happy with that and go back to sleep for a while or just say "look I want to lay in bed for a while" or we might have someone that normally does that, but on a particular morning when we can see that they're getting up earlier or vice versa they're normally up early but um that particular day they're just maybe just not quite right, they might be poorly, they might um… I don't know, just be extra tired cos they had a late night the night before, so we'll let them lie in. (CSF62)*
Table continued next page				

Medication	2	6	4	CSF31 goes over and plugs in the CD player and presses play. Rock and roll music plays and MR31 starts to dance in his chair. He looks happy and animated. ‘You love this one, don’t you?’ ‘Yep’. ‘Can I give you your yogurt now [name]?’ ‘yes please’. CSF1 has mixed the crushed meds into the yogurt and feeds it to him leaving 2 spoonsful, then she gives him his 2 liquid meds and then the last 2 spoons of yogurt[5]. ‘There, all done. What would you like for breakfast today?’ ‘mmm’ ‘Not a repeat of yesterday?’ she winks, and he laughs. She turns to me and tells me that he had Weetabix, porridge and toast yesterday. He laughs again and smiles at me.
Where to go (inside the home or grounds)	3	5	18	*CSF62: I managed to get a lady that doesn’t normally come to the dining room to eat in the dining room today… and she had her hair done, so she come back … from the hairdresser, and she was like “Oh um” you know “what do I do now?” so I said “Well why don’t you come and sit in here?” and she like ummed and ahhed, but I got her in there. She sat with another lady and they had such a lovely conversation…having a chat to someone rather than just falling asleep in her chair in her room and not eating much. She ate well, she chatted and then managed to persuade her “oh let’s go and meet some more people”…We encouraged her because I think if we’d just said do you want to go back to your room she would have “Yeah ok” and she would have just gone back into her room but you know we “come and sit in here”* RD: What information did you give her that helped her to participate in that decision? *CSF62 - Umm “you’ve just had your hair done, you look lovely, come in and show us”, you know*
Going out	2	4	18	*FR350…you know if visitors come to me and they take me out - I mean really that’s* ***their*** *decision, they, I mean, I’m happy to go but it’s their decision to take me (laughs). You know…so* *RD: Would you have any input in that decision?* *FR350: Oh well they will say do you want to go to that restaurant, or that pub or somewhere, and so, I make, sort of decisions, but not big serious ones.*

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[5] The administration of the medication (crushed into yogurt) had been prescribed by the GP and absorption rates checked by the pharmacist. The medication was not covert - it was the persons choice to take it in this manner as he found swallowing the tablets difficult and the taste unacceptable.

Management	1	4	3	ACM03 laughs and says that he tries to keep the activities interesting.” I have never organised Bingo! But I would if they wanted it. We have a residents’ committee and they ask for what they want, and I try to organise it if I can”. I ask about the people living with dementia. “some of them are on the committee too. Sometimes they ask for things and sometimes they just agree with activities that other people have suggested. We try to include everyone.”
Who to spend time with	2	3	15	CSF4 to MR10 – ‘Do you want to sit?’ ‘No’ Slow music starts to play, and he pulls her into a dance hold and starts to dance for maybe 10 seconds, she joins in, he lets go and leads her back to the dementia unit door.
Care of personal space and objects	0	3	1	*I took her to her room and showed her her stuff. I told her we need to put things somewhere else, mainly her puzzles cos she has loads and even the manager said it was a risk for fire…and we need to change that. So, I explain to her and I take her and show her where I am putting her stuff; she was OK with that…I think she needs to see where her stuff goes, that’s the main thing. If she doesn’t know she’s panicking she is talking not too nicely, she is swearing a lot, she doesn’t, er, from my perspective she needs to be participating. If she saw where her stuff goes she is more happy so she knows instead of someone just move her stuff where they think. You show her maybe this goes there… (CSM5)*
Who to go to for help	0	2	5	*Well, there’s an office down the stairs and erm, if I couldn’t, if I couldn’t ask ACM03 (pause) I’d just ask the people at the office. It’s never erm, come up, I must admit, so I could, I could, it depends on what it’s about, that’s it (FR023)*
Communication	0	2	3	*CSF61: When I first offered FR06 the cards she didn’t use them. We had 2 types. Bigger individual cards but they were too hard for FR06 to manipulate, and these [plastic cards on a keyring]. She threw them at me once or twice (smiles). Anyway, I left them with her and she can use them a bit. For example, there is a card for ‘I don’t like it’ and another for ‘I like it’, and of course the one that you use the most FR06 (laughs)* *FR06: smiles and nods. She sorts through the cards and finds a picture and word card that says, ‘too hot’.* *CSF61: laughs. FR06’s always too hot!* *FR06: Nods and laughs* *CSF61: So, I guess FR06’s good decision may be to start using the cards? (Looks at FR06 for confirmation)* *FR06: nods twice*

Table continued next page

Medical attention	0	2	2	*I said "oh, I'm coughing again" and she heard me and so she said, 'maybe you should see the Dr?' so I agreed and saw the Dr last week and started them [antibiotics] Thursday night. That was a good decision cos I couldn't go on like it (coughs). (FR350)*
Faith activity	0	2	0	Over 45 minutes, a FR with advanced dementia told me about how a care worker had organised for the vicar to come and visit her on a weekly basis. This was obviously very important to her and she proudly told me about how they had talked about it and decided on when the vicar should come. The conversation was protracted and difficult to represent in quotes.
Smoking and Drinking alcohol	1	2	0	ACM03 'That's about it [name]. After breakfast I will take you out for your morning cigar if you like?' FR039 'That sounds pretty damn perfect! Brekky now – coffee and cornflakes!' Both laugh. ACM03 'Lovely, I'll take you back now'.
Physical activity	2	1	1	MR walks slowly down the corridor with CSM. He calls along the corridor and CSF01 comes out of DR to encourage him. She stands by the DR door and calls to him. They are laughing, and he is teasing her. She calls "you are only walking to see this beautiful woman" MR laughs. CSF01 to CSM "walk behind him. He is not used to walking." Then to MR "Look at you peeking round the corner." MR says "he's wheel clamped my wheelchair" CSF01 "oh dear. You are looking good though".
Money	1	0	20	MR comes back in 'How can I get to [name of town] ACM03?' starts to get a little agitated 'I haven't had a round coin to spend for a month or more. I need to get over that bit of road…' ACM03 'I can take you on the bus on Thursday if you would like to go to town?' MR035 calms down
Hair and beauty	0	0	1	*If someone wanted to see the hairdresser, then I would say "Well the hairdresser comes Monday or Wednesday after lunch. Have you got a preference?" And they would come back and tell me the preference. (CSM51)*

Italics denote speech in an interview or focus group. MR – Male Resident, FR – Female Resident, MV - Male Visitor, FV - Female Visitor, CSFN – Care Staff Female (Nurse), CSM - Care Staff Male, CSF - Care Staff Female, ACM - Activity Coordinator Male, ACF – Activity Coordinator Female, RD – Rachel Daly (researcher)

Spectrum of decision making

To ascertain how the levels (or spectrum) of everyday decision-making was implemented and understood, data from observations, interviews and focus groups were mapped against Thompson's (2007) decision-making taxonomy as extended by Smebye (2012)(see Table 19).

Table 19: Levels of Decision-Making Involvement with Definitions (Smebye,2012)

Level of decision-making involvement	Definition	Number of examples
Non-involvement	Non-involvement where people living with dementia were passive recipients of care and treatment	67
Information seeking/receiving	Asking for potentially relevant information, an elementary stage of participating in decision-making	3
Information Dialogue	Discussing options but decision being made by the staff or family care partner	29
Shared Decision-making	Demonstrating a level of dependence on others when participating in the decision-making process but co-operating and/or negotiating to finding solutions; both parties' opinions are considered	101
Pseudo-autonomous decision-making	Apparently making autonomous or implicit decisions but being unaware of all available situational choices, or staff and family care partners supporting decisions based on false assumptions from pre-existing knowledge	48
Autonomous	Decisions made independently. Staff and family care partners offered information and where appropriate checked for a rudimentary level of understanding to facilitate decision-making	69
Delegated	A conscious decision to authorise others to decide on their behalf	2

There were almost equal numbers of autonomous decisions and non-involvement in decision-making. Autonomy was widely recognised and discussed by participants, although how participants defined, or perceived autonomy varied. For example, 'autonomous' decisions were sometimes facilitated by care staff clarifying options, manipulating environments and being clear and concise about the choices available. Care staff often demonstrated how they communicated choice using visual aids and physical props to compensate for dementia related confusion and reduced concentration.

Stories of non-involvement in decision-making came from staff and family care partners and predominantly depicted a person who was (or was perceived to be) incapable of participating in decision-making because of the advancement of their dementia or because they were sleeping. Family care partners were less likely to involve their partner living with dementia in an everyday decision in the care home than the care staff were. For example, in an extract from an interview with MRF05 (on page 111), she highlights that she would know what her husband would want because they had been together for so many years. There were few examples observed of people being present and simply not being given the opportunity to participate in a decision and this tended to be due to a lack of available choices. (An example was the route of administration of a medication.)

Shared involvement in everyday decision-making was most evident when people living with dementia had problems understanding the decision or needed additional time to consider available options. The process for staff was often one of checking and reiterating the residents’ choices. Staff and family care partners used questions, repeated information, reduced or extended choices and offered their own views to help residents to make decisions. Distinguishing between Smebye’s (2012) levels of ‘information seeking, information dialogue and pseudo-autonomous decision-making’ was often difficult. They all involved negotiation or support in the information exchange and therefore included an element of shared decision-making.

Some staff appeared to have a particular aptitude for, and commitment to, involving the residents; one member of staff on a high needs dementia unit in Eden Valley used opportunities at mealtimes to engage with residents. She took extra time and offered additional choices to involve people in their decisions;

> CSM asks CSF45 “what shall I give to FR [name]?” CSF45 asks “what’s the choice?” looks at the choices and then takes the menu and asks residents individually “would you rather have steak and ale pie or cod today?”. She asks the CSM to help a FR with her main course. She goes to MR03 with his pie and mash “would you like sauce with that?”, “yes please”, “red or brown?” “brown please”, “mm nice bit of brown sauce with your pie”. To FR “would you like steak and ale pie or cod in tomato sauce?” FR pulls a face and shakes her head. CSF45 asks “would you rather have a sandwich?” FR puts her thumb up and winks. CSF45 “cheese?”, “yes please”.

Pseudo-autonomous decisions were dependant on contextual and relational factors, such as where the resident was and whether the member of staff knew them well. There were examples where care staff were seen to be attempting to involve and inform the person even though they did not appear to be expecting a response. In other instances, everyday decisions were implicit and lacked any dialogue. Within both the care homes there was inevitably a level of environmental and or organisational influence on everyday decision-making (for example, meals had limited choices) and routines were predictable. This influence was extended to freedom of movement in the five out of six dementia care units that were locked.

Delegated decision-making was rare and only identified in two interviews. Neither example was of a resident delegating a long-term decision, more that they didn’t want to make a specific decision on a given day or at a given time. For example, a resident participant in Eden Valley was clear that some days he wanted to be ‘involved in the detail’ and other days he was happy for care staff to make decisions on his behalf.

There were examples of care staff being careful not to make decisions on someone’s behalf and although the sharing of the decision was implicit, it was clearly present in this example from a high needs’ dementia unit in Treetops:

> *CSF4…I do get to know what they prefer and what they would like so, sometimes I know what they would like. But then everybody would like a change now and again so you can’t just be complacent that “oh Joe Bloggs likes cornflakes everyday”, you know, some days he might not like cornflakes,*

> *he might like something different so you've got to just kind of, just help them decide, and you can, you can show them a bowl of cornflakes – and I'm not being funny, if they don't eat it you try something else. So, they can have 3 or 4 bowls at the table and they can pick which one they like.*

Negotiation and compromise were a common feature of shared decisions. Care staff sometimes offered additional information, reassurance or encouragement to achieve what they perceived as a preferred outcome. However, there were examples where the care staff compromised and cooperated with the person living with dementia, even if they were not particularly comfortable with the outcome.

> *CSF22: …once a resident didn't want to get dressed at all and wanted to stay in her vest…and I did try and encourage her and she still didn't want to wear it and I go "can I put a blanket over you just to give dignity, and I'm gonna shut your bedroom door so that you have got that privacy … cos you're not putting any clothes on" and then she was fine with it. And I told her family that she doesn't want to put clothes on … and I wrote it down ... She didn't want to wear a blanket either… but she was happy as Larry and she was like "I'm not putting them on…I don't wanna wear them". The next day, I think she got dressed and then she stripped all her clothes off and chucked them at the carer (laughs). And … I was like, "it's probably the way you approached her, you have to be like really calm and lovely" …Mmm. (Treetops)*

Food and drink decisions were predominantly shared in both care homes, and this was the field where people living with dementia and communication difficulties were most likely to be given the opportunity to change their mind.

Decisions about daily activities, what to wear, going out, physical activity, smoking and drinking and medication timings were also predominantly shared. However, decisions about when to get up or go to bed and personal care were predominantly perceived to be autonomous by all participant groups. Where to go in the home or grounds and who to be with were also perceived to be autonomous by all parties.

There were areas of the management of the home (such as organised activities and menu planning) that were perceived to be a shared decision by staff in one of the homes but not in the other. The home where staff talked about shared decisions in management (Eden Valley), had monthly planning meetings involving staff and residents. Discussions focused on organised activities that could be added to the programme and possible menu changes. I was present in the home on two occasions when these meetings were taking place, but none of the residents that I interviewed attended the meetings. Treetops staff and residents did not perceive the home to have shared decisions regarding home management and yet I saw posters on each unit inviting staff and residents to meet the chef to discuss the menus.

Opportunities for decision-making

Two unanticipated themes about decision-making opportunities emerged from the data. Firstly, the opportunity for people to change their mind about a decision that they had made appears to contradict the findings of the systematic review – this is discussed in the '*Time and Environment'* section of the Discussion Chapter (6). Secondly, care staff that had personal experience of dementia affecting a family member appeared to be more prone to taking additional time and offering a broader range of choices to people living with dementia to increase their opportunities for choice.

People changing their mind

During the analysis of the discovery data there were multiple examples, in both care homes (n =12), of residents changing their mind about everyday decisions that they had made. These instances were usually accommodated or facilitated quickly and quietly with minimal disruption, although there were occasions where this caused care staff considerable additional time or effort. Sometimes the staff thought that the person was not changing their mind so much as taking time or needing additional prompts to process the decision.

Examples of where people living with dementia were clearly changing their mind were predominantly related to food choices but were also about where to sit and who to spend time with. For example, the extract below is from an observation in a high needs dementia care unit in Treetops:

> Time 12.55 – CSF asks FR82 “do you want a table here?” “Yes”. CSF gets a table, gives FR82 a glass of juice and a glass of water before she exits. FR82 “Thanks”.
> Time 13.01 – FR82 calls out to CSFN “I don’t know what I’m doing here. They’ve put me here, but I was with those other ladies. Those 2 ladies’” points to CSF and another FR in the dining room. CSFN “they have gone to the dining. Do you want to go to the dining?” FR82 “well that’s where I’m supposed to be!” “OK. I will go and make some space for your chair” she smiles and slides the table out and walks to the DR. CSM takes FR82 out to the dining room in her chair and then comes back for the table. (High needs dementia care unit - Treetops)

Personal Experience of Dementia

Care staff participants (n=5) who had disclosed personal experience of caring for a close friend or family member with dementia appeared to have a greater desire to engage with people living with dementia. These staff often stayed late, came in on their days off and brought their children or dogs to visit the residents. Their level of empathy appeared to be higher and they wanted to provide more time, promote greater choice and demonstrated a level of patience and creativity that was not always so noticeable in other staff.

> *CSF22: …I know if you give them too many choices they can get confused, but if you give them limited choices, it gets boring.*
> *RD: So, it’s trying to get a balance?*
> *CSF22: I think it’s good to know all of their likes and dislikes… and if it’s like mealtimes, if they don’t want a certain thing, like give them different options like macaroni cheese, … mushroom soup, chicken soup…and we’ve got tins, so we can just show it to them and they can pick out which ones they want.*
> *RD: If they don’t like what there is you can…*
> *CSF22: Yeah, we always do anyway down in [high needs dementia care unit]. MR [name] will sometimes say that he doesn’t want to have [inaudible] at lunch time, so I’ll make him some toast and save his lunch for evening…(Treetops)*
>
> *CSFN31: … To be honest, I feel like each resident will be* ***mine. My*** *grandmother (starts to get tearful and tells me about her grandmother – I*

> *gesture to switch off the voice recorder. CSFN31 shakes her head, no) …and that's why I try to do my best … Because my grandmother was in a nursing home as well… Here … most of the worker, they are really good with the resident… sometimes it's difficult because you've got 15 resident and it's not easy when you would like to spend more time with one person, you have to [inaudible] tasks. Is difficult. It's my (pauses) complaint! (laughs).*
> *RD: OK, so how many [care staff] would you have?*
> *CSFN31: One per, for every resident! Exactly. Yeah. Spend time and do exercise and do activities and chatting, many things, knitting…any…any! (Treetops)*

Factors that enabled Everyday decision-making

Six ways in which staff and family care partners enabled people living with dementia and communication difficulties to participate in decision-making processes were identified (Table 20). The factors were broadly classified as:

- Encouragement
- Communication
- Choices
- Environment
- Decision partner
- Time

Some enabling factors were skills that staff had learned from training or colleagues (such as reducing choices) and others appeared to be inherent personality traits (such as compassion and patience) that eased the decision-making process for people living with dementia and communication difficulties. Staff and family care partners were observed taking additional time and effort to support shared everyday decisions. This worked particularly well where people living with dementia and communication difficulties were positioned as being competent or capable of making a decision.

> *CSM6: … She is not speaking clearly but she can point and make her choices and if you make choices for her, she will really kick off, because she wants to be in charge, and she is still capable. Why would I take that ability to make that choice away from her? So she always chooses what she wants to wear, including socks and everything.*

Table 19: Key Messages of Enabling Factors

Enabling Factor	Key Messages
Encouragement	Motivational support for a person living with dementia to do something that is considered to be in their best interest, or confidence to try something new.
Communication	Tailored multisensory approaches (e.g. simplifying language, breaking down compound decisions, using visual aids) to facilitate decision-making processes.
Choices	Choices are; 1) simplified by offering only two choices or 2) expanded by offering all available options with relevant information and advisory support.
Environment	Care home routines and physical environments are manipulated to facilitate multiple individual preferences and participation in decision making.
Decision partner	The decision-making process (including who is involved) is shaped by the preferences of the person with dementia and the decision to be made.
Time	Time and space are provided to facilitate decision-making for people with fluctuating capacity and enable 'in-the-moment' decisions.

A member of Eden Valley staff who was working with a resident in the gym checked to make sure that he understood what he was telling him, and reinforced verbal information with physical gestures. He also offered support in the form of reassurance when the resident wanted to check the appropriateness of his attire;

> ACM03 asks “would you like to do some exercises today MR35?” “Will you show me what to do then and do it?”, “Yes, I'll show you and count you down”, “what do I do with this?”, “Here” ACM03 puts the handles into his hands and shows him the exercise. “do you mind if I take this off?” (gestures to his jumper), “yes take it off MR35”, “I best check what I've got underneath”, “You've got a shirt on, it's fine”

There were examples where care staff instigated a shared decision by offering an alternative to what the person living with dementia was doing that included a range of options or choices. These were often limited to one or two alternative choices to simplify the decision-making process. The care staff then clarified the choice to promote a shared understanding of the situation.

> *RD: What made you… ask her if she wanted to go for a walk?*
> *CSF6: she was just sitting and looking at the tele, but she… was just like she was looking to something and I said maybe will be better if I take her from here away because everybody was sleeping so… it would be a good thing just to walk around, or go outside for a walk, or just to sit up outside in the garden. But I asked her to sit down outside in the garden and she said it was a little bit windy, so she preferred just to walk inside the building. I just asked her "FR26, what would you like to do? If you want to go outside, we can sit outside in the garden, or we can walk just inside in the building and we can visit some other ladies and gentlemens from your age?" and she said "oh, that would be lovely!" so I just took her around and she liked that! (Treetops)*

Positive relationships (including relational understanding and trust) appeared to be important in the facilitation of shared decisions. For a decision to be shared, a level of mutuality and interdependence appeared to be essential. However, strong positive relationships alone were not enough to enable shared everyday decisions. This was particularly noticeable with all three spousal care partners who had been together for many years as demonstrated in this interview in Eden Valley:

> *RD: How do you help him with decisions about his care?*
> *MRF05: (long pause) I don't really know to be honest. Whatever you say he, just goes along with.*
> *RD: He wouldn't get upset if [care staff] …for instance, picked out a pair of trousers he didn't want to wear?*
> *MRF05: No, wouldn't bother him at all. No, he's very easy… I know what he likes, what he doesn't like, but that's just through be, being with them a long time etcetera. And you wouldn't really have to think twice! I mean, you'd always* ***ask*** *them, and er, but I'm sure you'd know,* ***I'd*** *know what he's gonna say! Yeah.*
> *RD: If you held up 2 things, would [name] be able to choose which one he wanted?*

> *MRF05: I don’t know. Cos I’m not here when he’s got food or anything like that, so I don’t, I don’t really know. He’ll eat anything, if you know what I mean, he’s not fussed.*
> *RD: …do you feel that you (pause) lead his choices by suggesting something to him, such as “do you want a milkshake”?*
> *MRF 05: That’s right. So, he wouldn’t turn around and say “no I want a cup of tea” – If I said “do you want a cup of tea?” he’d say “yes”, he wouldn’t say “I want a milkshake”*

Care partners were clear that they would ‘check’ that they had got the decision-making right, but that largely their partners were either no longer able, or not particularly interested in participating in everyday decisions.

Encouragement

Encouragement was widely used in a range of different ways to support decision-making. In some instances, this was to encourage the person living with dementia to behave in a certain way that was perceived to be in their best interest, such as maintaining their independence or having a wash to maintain skin integrity. In other situations, it was about giving them confidence to try something different or new.

> *CSM5 – the first time we came here, FR [name] used to stay only in bed… and er one time I said … “Let’s get you out of bed for a while” and from then she is always in the dining room. Yeah, she even buzzes now for to get her out of bed. She wants to stay in the dining room and talk with somebody. (Treetops)*

Communication

The ways in which people communicated had an impact on the shared decision-making process for people living with dementia. Clear, simple speech, attentive listening and making eye contact were invariably used in everyday decision-making communication. Care staff in both homes, were skilled at deconstructing complex decisions, clarification of shared understanding, reiteration of available choices and potential outcomes of the decision in question were also consistently used. Although there were no stories related to receptive communication, staff and family care partners were seen to be attentively listening on multiple occasions in both care homes. Some staff tailored their communication depending on the environment in addition to the individual they were communicating with, whilst others used three or four approaches and combined them as appropriate to the resident.

The most common expressive communication aid used by staff and family care partners was stimulating multiple senses to facilitate the decision-making process. Pictures, objects and gestures were widely used visual prompts in both care homes. Food and drink and clothing were most often given as examples in discovery stories;

> *CSM3: … the more senses you can involve in a decision the more you can get information across to people…so for instance at lunchtimes when we ask people about what drink they would like, I would put the cartons in front of them, and point them out and say them so that they can see the choices and hear the choices at the same time. (Treetops)*

There were examples of multiple senses being used to compensate for other communication difficulties. During observations care staff were regularly seen using touch and verbal support, especially in the high needs' dementia care units. Here a member of staff told me about a blind resident living with dementia in Treetops;

> *CSF6… FR [name] – she cannot see, so we have to tell her what she's eating, what is the lunch, what is the pudding ...*

Multiple senses, including the use of taste and smell, appeared to be used by some staff to compensate for the effects of the dementia itself. The length and/or strength of relationship between the care staff and the person living with dementia was also evident in some stories. Care staff used their knowledge of the person to recognise subtle changes in them. Then, importantly, combined that knowledge with skilled communication to identify when they could expect a congruent response from that person.

> *CSFN31: sometimes is difficult when you offer something, and they say "no" but then …you put something, like a plate of porridge, in front of them, they try to start to eat it. Maybe they refuse before but then when they try one sip,*

> *they start to eating. So sometimes it is because they don't know what we are talking about…*
> *RD: So you would use more than one method to communicate with people?*
> *CSFN31: Yes, we would try more than one ways to communicate, sometimes it is physically. Physical communicate, so you can see the person (gestures), and sometimes you know the person is very bad because you know his face or her face, you know how she is and you can see that his face…is not like usually. This person is not good at all! Maybe she doesn't tell you anything but doesn't need to because you know her face. It is important. Very, very important! (Treetops)*

The ways that people interacted and used language were also important; combining factors to achieve the best result:

> *CSF4: I tend to try and communicate to them, speaking slowly, directly to their face, so they can look at me. If they don't do that, then either in their ear so they can hear me and if they don't do that, I try and do a little bit of sign language (gestures with her hands), whether you want a drink or food. Erm, if I find I can't do that then I will try and pick up something to demonstrate what I am trying to say. … if I know that they would know what they would eat, I always will say "would you like cornflakes, Weetabix…" or whatever and I will offer a choice, so they could pick. (Treetops)*

Choice

There were differing opinions on the way that choices were presented to people living with dementia. Some care staff were clear that simplifying decisions by offering only two choices was a positive way of supporting people living with dementia to make decisions;

> *CSF 47: It's never been "a wash, or a bath, or a shower?" It's always been like, you know, "shower or a bath today? What would you like?" (Eden Valley)*

Whilst others believed that residents should be offered more choice and be given all available options;

> *CSF31 - in a way, just by giving that option of shower or bath, are* ***you*** *still making that decision for them cos you've only given them 2 options? … Cos actually, if they could, they would have a* ***wash*** *and you haven't offered them*

> *that. **Yes**, you can confuse them, but you're still kind of taking away some of that choice as well. (Eden Valley)*
>
> *CSFN31: I always just open cupboard and I say "what would you like to wear today, cos I think that they can choose whatever! **Any!** So…well they can choose between 2 trousers or between skirt and trouser, but I think they can choose between their whole cupboard. (Treetops)*

Environment

The environment appeared to be an enabling factor on macro, meso and micro levels. The macro level was the physical setting (modern, spacious and light, encouraging interaction), using clear signage and simple, clutter free, décor; and the care home culture, which was open to new ideas and participative action research methods. This was clear from the way that I was welcomed into each unit in both homes by residents and their staff and family care partners. Meso levels of facilitation included examples of where routines were built around the residents' preferences on some dementia care units. In this sense it could be perceived as high-quality person-centred care, however there were clear examples from my observations where negotiation had taken place to ensure that multiple people's preferences could be catered for. For example, medication times were incorporated into multiple residents' preferred care patterns:

> 08.48 am – we go to a FR room. Most people are still in bed and we pass doors that are open but with residents still sleeping. CSF31 explains that some residents have meds at certain times, so they have to wake them, but most people wake up naturally and call when they want to get up. 'That's why we don't do them in order. This lady has diabetes medication' She dispenses different meds (12 tablets) then knocks on the closed door and waits. 'Come in' she enters and pushes the door too behind her. 'good morning [name]. I have your tablets' 'good. I am thirsty' 'Here I brought you some fresh water. Can I put a light on? and if we can sit you up a bit so that you don't choke on your tablets' FR laughs a little 'yes alright' 'Would you like a cup of tea too?' 'Oooh, yes please' 'I will get one of the girls to get you one.' Comes out of the room with medicine pots. CSF33 passing with a shower chair '[name] could

> you get [FR name] a cup of tea please?' 'Yep will do'. (Dementia care unit - Eden Valley)

The environment was also used as an enabling factor on a micro level in positioning the person as capable of participating in shared decision-making. This was done in two ways; by using individualised signs, objects or signals to support orientation (enabling the person to feel more in control and more able), and by manipulating the environment to suit the person's needs. An example of this was when items were removed from the wardrobe or drawers and presented in a way that was more accessible to the individual when they are deciding what to wear that day, or commonly used items were placed in clear sight of the person. These micro level environmental factors were not always led by the by the care staff or partner as can been seen in this observation note:

> 11.40 am – A FV is asking a FR what she thinks of the clothes she has brought her. "What do you think of these?" "I like it but it's a little bit tight here" "I think it's because your feet are a little bit swollen, if your feet go down…" "yes, maybe" "I'll take them back, shall I?" "might be best" "Or maybe if I get some scissors…" CSF joins them "do you need me to put some name tags in?" they move towards the resident's room. "Now what about these bits, do you want them in a drawer or…?" "No" "do you want them out to look at?" "Yes, might do, mightn't I?" "Right, that's it shall I put it there?" Yes, that's lovely" … (High needs dementia care unit – Treetops)

Decision partner

People, rather than relationships, were identified as enabling factors because participants living with dementia did not always identify people with whom they had the strongest or longest relationship to share decisions. They primarily talked about independence in their decision-making but thought that care staff or partners may perceive themselves to be involved or to have control:

> *MR46: I make - to my knowledge I, they may think they make decisions for me, but they don't. (Eden Valley)*

The residents that talked about who they asked for help in everyday decision-making said that they would speak to the activity co-ordinator, the nurses or that they would go to the office. The majority of residents said that they would select a person to help them dependant on the decision to be made (see Table 18 for an example). A few residents talked about family members helping them with small decisions. These family care partners were sometimes spouses and sometimes adult children. In the extract below, a resident in a high needs' dementia unit in Treetops, struggled to communicate that her daughter had cared for her at home and continued to help her to make decisions about where to go or what to buy.

> *RD: Can you tell me about a recent decision that made you happy?*
> *FR26: Yes, yes all of that and then of course with the family. Especially like with [daughters name] who's brilliant, she's lovely and that's where that came (gestures to her trousers?). It's only a small one, there, but she's really good.*
> *RD: So does she help you to choose things?*
> *FR26: Yes! We would talk (smiles)*

Some residents had formed close relationships and friendships with each other, and this sometimes resulted in them making decisions together. These included who to sit with, what they would eat at meals and which activities to attend. These relationships were dynamic and went beyond routines and limitations associated with care home living. For example, two residents habitually sat together at mealtimes and appeared to have a close relationship:

> Time 18.13: CSF to FR "have you finished?" "I have" "would you like some dessert? There is rice pudding, banana or yogurt" "OK" then to MR 32 "did you like the rice pudding?" he ignores her. "Speak to yourself [own name]. Did you hear me? I asked you if you like the rice pudding? If you liked it, I will ask for that and you can have it." "Yes", "so shall I do that? Shall I get rice pudding or yogurt?" MR 32 "get yogurt". The FR asks for a yogurt. (Eden Valley)

Two female residents on another unit had an interdependent friendship. The lady with more advanced dementia had lived in the home longer and regularly shared the activities information with her friend. They spent considerable time together deciding which activities and outings to attend, with the newer resident sometimes supporting her friend by reminding her when an activity was due.

> *FR021: …she's very good, she comes with a, she's very efficient. She's got the paper in front of her and she comes and tells me and so we talk a little while and er…*
> *FR023: [shrugs and smiles] I'm not, but I do it all the same (Eden Valley)*

Time

Time was used and recognised as an enabling factor in three ways. Firstly, when people living with dementia were given extra time to think about their decision;

> *CSF01: you'll have one lady who you offer her medicine "Oh no I don't take tablets, it's not me" and then I do say 'OK, let me let her brain go around' and I'll give her a few minutes and I'll say, "Would you like your tablets?", "Oh thank you". (Eden Valley)*

Secondly when staff and family care partners recognised that some people were more able to make decisions at certain times of the day;

> *RD: So, you feel like they are more confused in the morning?*
> *CSF6: Yeah. Some in the morning, but we got, for example FR26, the new lady, she is more confused in the* ***evening.*** *This is something normal for her. (Treetops)*

And thirdly staff in both care homes considered the opportunity to make a decision 'in-the-moment' particularly important for people living with dementia. Residents did not identify the importance of in-the-moment decisions, but staff identified multiple examples about food:

> *CSF45: … so if they want a bit of each, they can have a bit of each. They can have whatever they want it's, we ask them when they're actually sat at the table. (High Needs Dementia Care Unit, Eden Valley)*

> *CSF22:…we will ask them the night before, even though they mightn't remember, and then I will ask them on the day again, to double check which ones they prefer, and then like with FR [name], she'll probably say "I don't*

> *want neither of them" and then we'll get her an omelette, cos she'll like eating an omelette so we just tell [kitchen staff] to make and omelette and he'll do it for her on the day. (High Needs Dementia Care Unit, Treetops)*

On a collective level, each dementia care unit had created ways of managing in-the-moment decision-making. Organisationally this was accepted, and enough food was sent to each dementia care unit to enable in-the moment decisions. However, residents living with dementia on nursing care units were unable to access the same level of flexibility:

> *CSM51:…giving the options the day before is because they need to be prepared and cooked and that's the only way we can do it but if there was a way that, 'it's lunchtime now, what would you like now?' because the day before you could be like, 'I'm really in the mood for…whatever' and then completely want something else the next day. (Nursing Care Unit, Eden Valley)*

Observations corroborated the importance of in-the-moment decision-making for people to maintain a sense of control over their lives; particularly with regard to food and drink, organised activities, personal care, going to bed and who to be with.

> 09.45 – Medication round: CSM1 gives MR47 medication – "would you like to take these? This is your calcium, here and [inaudible]" 'Yes thank you'. CSM1 moves on and dispenses medication for FR23 – "We need you to take these [name]. (Pause) Will you take them for me? (Extended pause). Could you have them with a cold drink for me [name]?" 'Yes…maybe. What can I drink?' "what would you like? Water?" 'Apple juice' "Apple juice?" 'I can't pay for it' "That's OK [name], I'll get these – I was having one anyway" 'well if you are sure then' (Dementia Care Unit, Eden Valley)

> 1.14 – Dining Room: FR8 to CSF9 'Is it OK if I get down and go through there?' "Yes of course" 'Thank you darling'. Looks around, gets down and leaves the room. (High Needs Dementia Care Unit, Treetops)

> 6.35pm – Dining Room: FR24 leaves the room (self-propels in wheelchair) and asks CSF24 'can I have a shower later, before bed?' "Of course, What time would you like to go bed?" 'Oh, I don't know. Come along to my room later and ask me?' "Yes, OK." (Nursing Care Unit, Treetops)

Summary of key findings from the discovery stage

The discovery stage of the 4D cycle revealed that in both care homes people living with dementia and communication difficulties were frequently participating in everyday decision-making that built on routine encounters. Twenty different decision-making fields were apparent. Whilst decisions were inevitably constrained by the choices available, care staff created opportunities for residents to be involved in discussions and planning about their day to day life and care in the care homes.

Although this shared decision-making did not always resemble what is typically understood by the term in a clinical sense, people living with dementia and their staff and family care partners were ‘sharing’ everyday decisions. Involvement was usually achieved through collaboration and negotiation using a combination of enabling factors including; communication, encouragement and time.

All the discovery information was used to inform the implementation stages of the AI study; the dream, design and destiny stages of the 4D cycle, which are presented in the following chapter.

Chapter 5 - Appreciative Inquiry Implementation Stages

Introduction

In this chapter the implementation stages of the Appreciative Inquiry (AI) are presented as they progressed from the dream stage, through design to destiny (see Figure 9).

At the beginning of the design stage, observations and participants' stories and dream ideas were fed back to them. This enabled participants to explore what they already did well and then reimagine if they could use the learning to improve choice and decision-making to be even better. No participants appeared particularly surprised by the data, although some stories triggered other care staff, to recall an episode or recite a consequential story. Consequential stories were those that were instigated by the AI process itself. Participants often used them to generate greater or more complex dream ideas or as a tool to pare down dreams to something more practical in the design stage of the process.

Participants were asked, "if time and money were no object, how could you make shared decision-making even better?" Participants were not prompted or directed in any other way. Seventeen ideas were initially proposed and discussed. These were mapped against the spectrum of levels of decision-making (Smebye et al., 2012), and any ideas unrelated to shared decision-making were not analysed further. Each idea was tracked as it developed throughout the AI cycle. Ideas that progressed through the design stage were analysed in the context of the decision fields and enabling factors identified in the discovery stage.

The dream and design stages of the 4D cycle involved interviews and focus groups; the destiny stage also included evaluative observations (Table 21).

Table 20: Number and Type of Data Collection Episodes in Each Care Home

Data Collection methods	Treetops	Eden Valley
Dream interviews	16	4
Dream focus groups	1	7
Design interviews	10	6
Design focus groups	3	6
Destiny interviews	6	2
Destiny focus groups	2	4
Destiny Observations	18 hours	18 hours

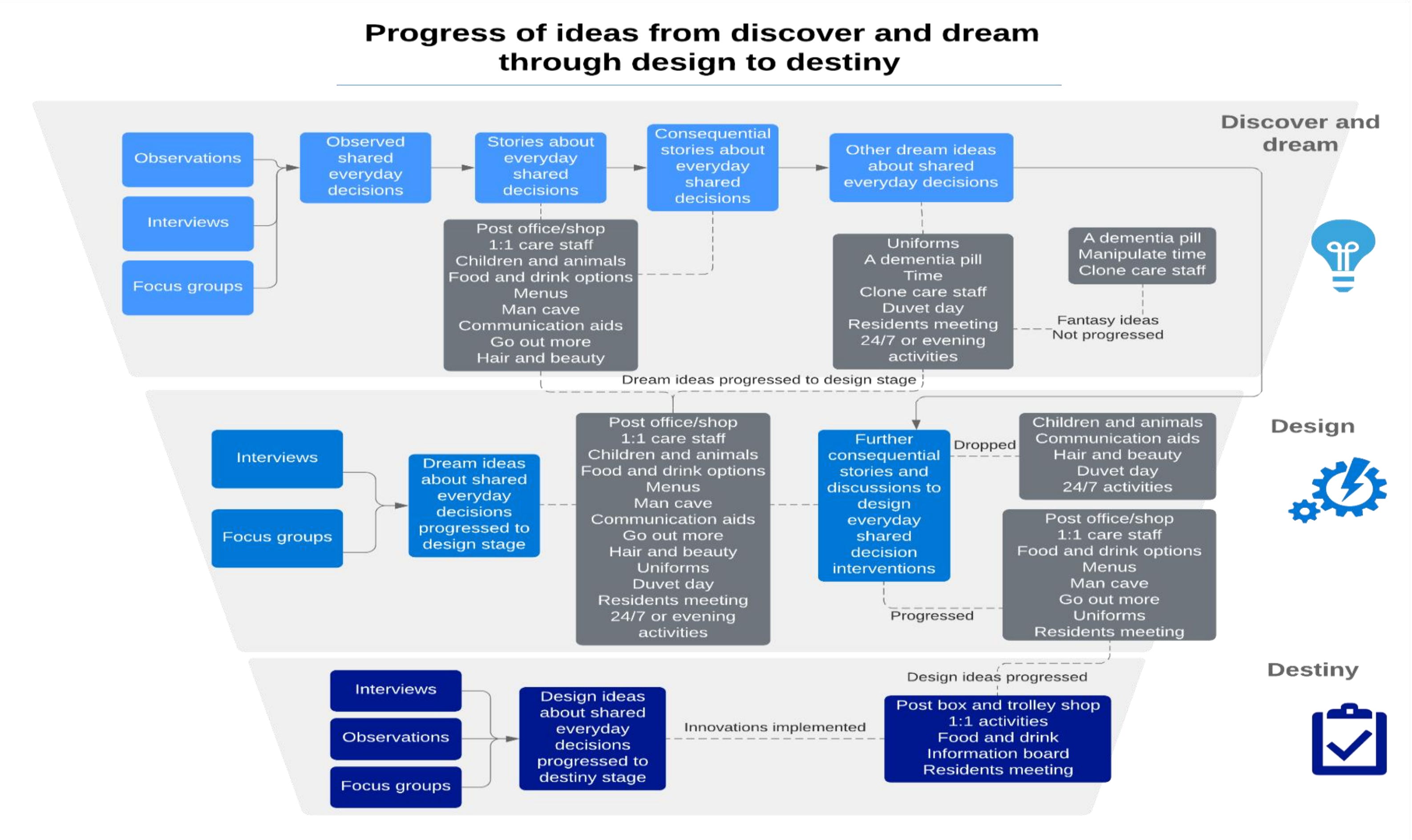

Figure 9: Progress of Ideas Through the 4D Cycle

Dream stage

All ideas were accepted at face value during the dream stage of the AI process. At this stage of the process ten of the seventeen dream ideas (59 per cent) stemmed from participant stories (marked with an asterisk in Table 22). This number grew as consequential stories were told throughout the dream and design stages.

During the analysis of the dream ideas, they were categorised as: Fantasy ideas (marked in red in Table 22), ideas unrelated to decision-making (marked amber in Table 22) and ideas that relate to, or facilitate, shared decision-making.

Table 21: Frequency of Dream Ideas by Source

Frequency of Dream Ideas by Source				
Dream idea	**Frequency**	**Sources**	**Treetops**	**Eden Valley**
Post office, shop or village*	20	5	✓(CS)	✓(CS)
1 to 1 care staff*	16	7	✓ (CS, FCP)	✓(CS)
Children and animals*	13	6	✓(CS)	✓(CS, FCP)
Food and drink options*	12	10	✓(CS)	✓(CS)
Menus*	12	6	✓(CS)	✓(CS)
Man cave*	11	3	✓(CS)	
Uniforms	10	6	✓ (CS)	✓ (CS)
A dementia pill	6	6	✓ (CS)	✓ (CS)
Communication aids*	13	7	✓ (CS, FCP)	✓ (CS, R)
Go out more*	5	4	✓ (CS)	✓ (CS)
Manipulating Time	3	1		✓ (CS)
Hair and beauty*	2	2	✓ (CS)	
Clone care staff	1	1		✓ (CS)
Duvet day	1	1	✓ (CS)	
Residents meeting	1	1	✓ (R)	
Activities				
- **24/7 activities**	12	2		✓ (CS)
- **Evening activities**	5	1	✓ (CS)	

Frequency is the number of times an idea was raised and discussed. Sources relates to the number of focus groups or interviews where the idea originated. CS – care staff, R – resident, FCP – family care partner, relates to the participant group(s) the idea originated with.

Food and Drink Options

The most common dream ideas (by number of individual participants) were related to food and drink options, with 83 per cent of the care staff participants across both care homes (n=20) having dream ideas relating to the food offering available. The dreams were diverse but had common threads of recognition of choice and the opportunity to make ‘in the moment’ decisions:

> CSF21: *…perhaps if we had like a school canteen where we could all go down and there would be like a selection and you could just choose what you want.* (Treetops)

> CSM51: *…you go round with the menu and I know there's things you can get off the menu like jacket potato or omelettes, but I think it would be nice to offer them you know like lobster or, if they got you know sirloin steak, this sort of dish, you know. Even if you get a nice restaurant, not just to have 2 or 3 options you know, to have many, many different options and obviously a lot of them have got small appetites, but if it's a la carte, just small portions…* (Eden Valley)

There were also consequential stories associated with some of the ideas. For example, during a focus group, a dream idea about the food and drink options combined with another dream idea about having pictures on the menus and prompted a staff member to share a story about one of her residents.

> *CSF31: one of our newer residents actually, he always says, “can I see a plated up before I – can I see what it looks like before I eat it?” So a real life picture would be – you know – rather than a, I know it sounds silly not like a… drawn picture or something like that, a picture of the actual meal on a plate…Because obviously I’m talking of a gentleman living with dementia, but he’s always, you still ask him “would you like fish, would you like pork?” “well can I see it on the plate before I eat it?” (Eden Valley)*

Post Office, Shop or Village

The dream of having a dementia friendly village, shop or post office in the grounds of the care home was the most frequently discussed idea, although it only originated from five out of 20 dream focus groups and interviews across both care homes. A total of 13 care staff participants (54 per cent) shared this dream and revisited and discussed it repeatedly. The dream was outside of existing practice within the homes. Participants thought that it would improve wellbeing by facilitating shared decision-making through increased choice and activity and get people outside in a safe environment.

> *CSM51: I would have a… big complex … like a community. They would have their own apartment, own bedroom…on its own so it's your house, your front room, your kitchen, but then there's like a restaurant - you go out for dinner so you go to the restaurant ... and there'll be a pub, there'll be everything... there'll be a little shopping centre I mean with little stores like Marks & Spencer... Waitrose, Sainsburys, little shops and then everybody would have a carer. (Eden Valley)*

In Treetops a member of staff had seen a documentary about a dementia care complex in Florida. The excitement in the room was tangible. This excerpt from a focus group demonstrates how the care staff fed off each other and the dream started to develop and grow:

> *CSF 31 - I want a dementia friendly town like they've got in umm…*
> *CSF47* – *YES!!!! Have like a tuck shop, all of that*
> *CSF 31 - a shop built in the grounds…*
> *CSF65 - a little coffee shop … a bank cos everyone keeps asking to go to the bank*
> *CSF47 - Bank, post office*
> *CSF63 - oh yes. Oh my goodness! it'd be amazing*
> *CSF47 - it is really, really, good. it's a real place. it's amazing. Did you watch the documentary of it?*
> *CSF63 - oh that would be amazing.*
> *CSF 47 - honestly that would be so good for some people that want toiletries and that they are like "oh I'll pay you money, I'll pay you money"* – *"no no no it's already sorted your family have bought it". "No, I'll pay you money, you go in for me… you've got it". It would be so good if they actually had like a mini post office with*
> *CSF 65: a bank cos everyone keeps asking to go to the bank*
> *CSF47: A mini Tesco's yeah*

Another focus group in Eden Valley had a similar dream but this one focused on the idea of a post office, which would fulfil people's desire to choose and buy things, and to promote written communication between residents and their families.

> *CSF 47: … not only that it starts a little bit of a pen pal with the family.*
> *CSFN01: Yeah and they can write something to family and…*

> *CSF47: … I've got loads of residents, where their family are forever travelling all the time and their only communication is* ***receiving*** *a postcard…*
> *CSFN01: … we have a person who is all the time erm postcards from family because they are on holiday and even if she is not able to communicate, she likes to receive and could be nice to help that person and show that maybe we send something? …*
> *CSF64: Instead of taking that card down to reception they would go out in the garden and say to the post office…*
> *CSF 47: We can have a post box!*
> *CSF 31: then all we have to do is empty that*
> *CSF31: and take it to reception.*

Three participants highlighted that they did not need a post box to support their residents to write to their families, but the conversation quickly moved forward anyway. This may be because at this point the participants were animated and excited and the brief was that they could think of anything regardless of resources. They talked about making a post box or suggesting that the residents make one as an organised activity. The discussion then moved back to how the post office or shop would look and how it would work.

1:1 Care Staff

Individual or 1:1 care staff was popular with nine participants (including a resident and a family care partner) across both care homes. This was thought to facilitate shared decision-making by allowing a carer to get to know the person with dementia better and giving them more time to be able to make decisions together. Despite the popularity of this idea some participants were quick to dismiss it with comments such as:

> *FRM16: I'm sure if people had more time to spend with them, something could come out where they're indicating, yes or no, if you like…like a 1:1 if you like, but that will never happen" (Treetops)*

'Man Cave'

The idea of a 'man cave' derived from care staff recognising that the activities in the home, including a relatively full, organised activity programme, focused predominantly on the female residents.

> *CSF4: If we … have activities and we have people come in to do things – you know a singer or anything – I would really like it if the men all got together and had their own*

> *little entertainment. Whether they had a man who come to do a bit of woodwork or come to do… something. You know specially aimed to them ...*
> *CSM5: Oh yeah completely. There's no knitting club for men!*
> *CSF4: Yeah and even you know just old magazines for them. I mean in Reception they've got no magazine to pick up and look.*
> *CSM3 – All the magazines we've got**…** really are like 'OK' and… gossip rags and that's all we have really isn't it?*

The 'man cave' was discussed 11 times in two dream focus groups and one dream interview - all in Treetops (a total of 7 participants, all care staff). The idea itself was not really about decision-making but about increased choice and environmental enrichment to promote wellbeing for the male residents, with some staff dreaming up ideas for the men based on assumptions and gender stereotypes:

> *CSF21: They could even do potting plants can't they... bulbs – men like gardening don't they, and that doesn't take a lot of effort does it? They could do the plants, put the bulbs in and…*

However, during the discussions, two care staff talked about identifying what the men wanted and including them in the design of the 'man cave' through a shared decision-making process in the form of a survey of the male residents to identify what the facility should represent and contain:

> *CSM5: this is not for us – obviously, I would just put my bikes in! (laughs) But we need to do like a questionnaire. It has to be done that way because (All start talking at once) "I want to do football", or "I want to do this"*
> *CSF4: You're going to have to go round and ask the men who's potentially going use it what they want because, you know, one might like football, one might like cricket and one might not even like sports, you know. One likes old cars, one likes modern motorbikes, you've got to – you know what I mean, you've got to have um….*

Key people

Some staff participants offered to champion ideas or take actions forward. Others were nominated or selected by group consensus. This did not always appear to be dependent on their job role or whether they were present at the time. Below are some examples from focus groups that how 'key' people were selected to progress ideas through the 4D cycle.

> *RD: … would one of you be happy to speak to the Kitchen …?*
> *CSF64: Yes.*
> *CSF31: You got the easy job (laughs) … and then I think CSFN01's job as she is the nurse is to make sure we do what we were meant to do*
> *CSFN01: You want to involve me! (smiles broadly)*
> *CSF31: CSFN01 can be the overseer*
> *CSF47: The hassle joiner*
> *CSF31: and supporter*
> *RD: are you happy to support these projects CSFN01?*
> *CSFN01: Yes! Of course, I will!*

In Eden Valley, CSFN01 was pleased to have been selected by her colleagues as a senior member of staff who they identified as supportive.

> *CSF65: Well some have got cinemas. We can have our little corner shop.*
> *CSF45: OK you gonna ask 'em then?*
> *CSF71: No. You can!*
> *All: Laughter*
> *CSF71: … and you could get one of [the activity co-ordinators] involved.*
> *CSF45: You could, I think one of them should be involved actually…*
> *CSF71: I've got [a resident] on my unit that probably would be involved. MR [name].*
> *CSF65: … he'd love helping out… he was doing the gardening. He was telling us what to do with the plants. I think on my unit it would be very difficult for people to help out.*
> *CSF45: But they could just sit there and watch it… I think it would be good. FR [name] would probably get involved.*
> *All: (start nominating residents who might like to be involved in the design and implementation)*
> *CSF45: … Speak to FR [name] because she is the residents'… co-ordinator… FR [name]'s got quite a bit of influence … So, if we put it by [her] and*
> *CSF71: and if she says she likes the idea… we might have… a better chance.*
> *CSF45: We'll speak to all of the um other team leaders and get the carers onside as well. And activities.*

Again, in Eden Valley, staff were aware that certain residents appeared to have greater influence than others and that employing them in the process could enhance progress. Confidence, enthusiasm, strong communication skills and inclusivity appeared to be important characteristics displayed by the 'key' people.

Conclusion of the Dream Stage

It appeared that participants enjoyed the dream stage of the AI 4D cycle. They said that they liked the freedom to suggest anything, regardless of how ‘ridiculous’ it seemed. Points that I noted from this stage of the process were:

- There was a lot of laughter; especially in the focus groups and the shared interviews.
- The care staff enjoyed being together and sharing ideas with colleagues from different units within the home.
- Participants living with dementia and communication difficulties and their care partners apparently found the abstract nature of the dream stage of the 4D cycle to be challenging: Only one resident participant independently thought of a unique dream idea (a residents meeting). Equally only one care partner independently identified a dream idea (1:1 care staff).

Progression of Ideas to the Design Stage

All dream ideas were classified into three groups; those considered impractical by participants and therefore abandoned, those that did not relate to shared decision-making, and those that were taken forward.

Ideas that were Considered Impractical

Participants considered three dream ideas to be too unrealistic to consider further; the ability to manipulate time, inventing a magic pill that would make dementia disappear, and cloning specific care staff. All three of these ‘fantasy’ ideas, and the idea of a duvet day for residents, were dropped at the beginning of the design stage and not discussed further by any participants. The fantasy ideas were dropped because participants immediately perceived them to be unachievable. The duvet day idea was thought to be simple to implement in individual units and not worthy of further discussion.

Ideas Unrelated to Shared Decision-Making

At this stage the ideas organically developed into those that were about general wellbeing and those that related more specifically to shared decision-making. The ideas developed predominantly through individual thought processes and group discussion, with participants discussing ideas and telling consequential stories that led to the group generating ever more advanced ideas.

A number of the ideas were not directly related to decision-making, but were generated by care staff wanting to increase choices available to residents and improve their quality of life. For example lots of staff had seen a documentary about cross generational work with nursery children coming into care homes and felt that replicating that would be beneficial to their residents. Other popular ideas relating to residents' general wellbeing included getting people living with dementia out more, extended activities and ideas related to 'hair and beauty'. Ideas unrelated to decision-making were not analysed or reported further.

Ideas Related to Shared Decision-Making

The ideas that related to shared decision-making were mapped against the fields of decision-making and the enabling factors that were identified in the discovery stage of the 4D cycle (see Table 23). This analysis identified that:

- Most ideas related to multiple fields of decision-making.
- Participants regularly combined dream ideas, including those that related directly to shared decision-making with some of the ideas that were more generally about residents' wellbeing.
- Ideas were designed to facilitate shared decision-making in creative ways. For example, the ideas of the shop and the man-cave were designed to increase choice and enhance the environment in such a way that it would encourage people living with dementia to go outside and make in-the-moment decisions (about what to buy). It would also use multiple senses to augment communication. The shop was the only idea that was considered to employ all the identified enabling factors.

Some of the ideas were difficult to map against the fields and enabling factors of decision-making. For example, ideas about 1:1 care staff and communications aids had the potential to affect all fields of decision-making.

Care staff had an understanding about the logistics and financial implications of their dream ideas and used these as a justification for dropping some dream ideas during the design stage of the 4D cycle. These conversations were sometimes less positive, in that they were recognising the reality of the organisational resource constraints. The discourse associated with how staff manage less positive aspects of organisational culture in an AI process is considered in the Discussion (Chapter 6).

Table 22: Design Ideas Mapped Against Decision Fields and Enabling Factors

Shared Decision-Making Related Ideas Mapped Against Decision Fields and Enabling Factors			
Design Idea	**Related decision-making field(s)**	**Enabling factors**	**Linked dream ideas**
Post office, shop or village*	Food and Drink Physical activity Who to spend time with Going out Money Where to go in the home or grounds Personal care	Choices Environment Encouragement Communication People Time	Going out more Food and Drink options Activities
1 to 1 care staff*	All fields	Time Communication	Activities
Food and drink options*	Food and Drink	Choices Communication Environment	Menus Communication aids Post office shop village
Menus*	Food and Drink	Communication Environment Encouragement	Food and drink options Communication aids
Man cave*	Who to spend time with Physical activity Going out Where to go in the home or grounds	Choices Environment Communication	Go out more
Uniforms*	Who to go to for help	Environment People	
Communication aids*	All fields	Communication Choices Environment	Menus Food and drink options
Go out more*	Going out		Post office shop village
Residents meeting	Management of the home Care of personal space and objects Organised activities	Choices Communication Environment People	Activities

Design Stage

The design stage of the AI 4D cycle offered participants the opportunity to explore the dream ideas and to develop those that they thought had merit and were achievable. Some ideas were discussed more frequently in the design stage of the 4D cycle than in the dream stage. This was because all the dream ideas were shared with all participants, which meant that participants became aware of, and discussed, ideas that other people had proposed in other interviews and focus groups in the dream stage. The design stage of the 4D cycle took place between three and six weeks after the discover and dream stage for most participants[6]. As with the sharing of discovery stories, the sharing of dream ideas resulted in further consequential stories.

This meant that at the beginning of the design stage, eight of the remaining nine dream ideas (89 per cent) were grounded in participant stories (marked with an asterisk in Table 24). Despite appearing to struggle with the dream stage of the cycle, resident participants and family care partners were well able to discuss dream ideas that other participants had had.

Table 23: Dream Ideas Progressed in the Design Stage

Dream Ideas Progressed in the Design Stage				
Dream Ideas Progressed to Design Stage	**Total Frequency**	**Sources**	**Treetops**	**Eden Valley**
Post office shop village*	48	7	✓(CS)	✓(CS, R)
1 to 1 care staff*	16	8	✓(CS, R, FCP)	✓(CS)
Food and drink options*	3	2	✓(CS)	✓(CS)
Menus*	23	10	✓(CS)	✓ (CS, R)
Man cave*	13	3	✓(CS)	
Uniforms*	9	5	✓(CS)	✓(CS)
Communication aids*	17	8	✓(CS, FCP)	✓(CS, R)
Go out more*	11	4	✓(CS)	✓(CS)
Residents meeting	19	7	✓(CS, R, FCP)	

To illustrate how the design process worked, example excerpts from interviews and focus groups are presented below to represent key steps in the design journey for all the ideas progressed through this stage.

Post Office, Shop, Village

The idea of having a post office or shop in the grounds of the care home remained popular with all participants in Eden Valley. The original idea was pared down from a village complex to a market stall or a small shop housed in a shed or summer house.

> *CSF47: Well actually 'activities' are in the process of thinking about getting a tuck shop on a trolley.*

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[6] As previously described in the methods (chapter 3), some resident and care partner participants completed all stages of the 4D cycle in one interview or focus group.

> *CSF31: so that's a start!*
> *CSF47: But you could, technically, you could put a little stall outside you know like a marquee, like a market stall you could…*
> *CSF31: You could, you wouldn't have to build it as a whole – it doesn't have to be a whole village. But you could just have something…*
> *CSF47: But I want the whole village! (laughs)*
> *CSF31: I'd like the whole village as well, but when we're talking about we haven't got the space or the money … but we could do* ***a*** *shop or* ***a*** *market stall or something.*

Following feedback from the dream stage of the 4D cycle, the care home management talked about having a small trolley 'shop' going around the units for residents to choose and purchase their own birthday cards, newspapers, sweets and stamps. They thought that this could potentially fulfil the idea of a village, shop or post office. However, some of the care staff were keen to combine the ideas of having a shop or village in the garden or grounds of the home with ideas of people living with dementia going out more;

> *CSF31: they're doing the tuck shop anyway*
> *CSFN01: I think this is in progress…*
> *CSF31: Yeah that's kind of already being done I think (shrugs and looks down)*
> *RD: OK, when you said about having it in the garden, what was different?*
> *CSF47: I mean it's a change of scenery isn't it for them. It's not like a trolley coming to their bedroom.*
> *CSF31: Because a lot of our residents want to go out!... and just to get out and feel like you're going out* ***to*** *the shop.*
> *CSF47: Yeah*
> *CSF31: because technically you do you go out to the shop. You don't have the shop brought to your house and someone come in with a trolley and say, "chocolate?"*

For these (and other) care staff, the idea of the shop was more than just an opportunity for residents to purchase food or toiletry items of their choice. The shop was about the residents having a purpose to go outside in the garden (fulfilling decision fields; physical activity and where to go in the home or grounds), have the sense of 'going out' to the shop, spending money and being with their friends in a normalised environment.

> *CSF45: It'd be like a little meeting place – you know rather than just a trolley.*
> *CSF65: You can even put some nice table and chairs outside the little shop.*

> *CSF71: and like I said it's the feeling of being able to* ***go*** *to the shop.*
>
> *CSF45: and them thinking they are actually*
>
> *CSF65: Going out.*

The idea was also popular with participants living with dementia and communication difficulties when it was shared with them in their focus group in Eden Valley:

> *FR021: Oh, that's a good idea*
>
> *RD: You like that idea FR021? Would it give you more choice?*
>
> *FR021: Exactly! And if you don't want to go down to the high street or something… because there's nothing here that we can buy, either to eat or anything*
>
> *FR023: I think the same, it's quite a good idea. Mm hmm.*
>
> *ACM03: … the residents have money of their own but they don't really get an opportunity to spend it unless they come out on a bus trip and they take it to the gift shop… a shop in the garden will give them that sense of "it's my money still, I can spend it on what I want in that shop"… what would you buy FR023?*
>
> *FR023: Lots of chocolate!*
>
> *All: laugh*
>
> *FR023: Toothpaste, things like that*

Menus

One of most popular ideas at design stage was to make the menus more dementia friendly. This idea combined some of the dreams about pictures (as communication aids), stories of acts and enablers that helped individual residents, the food offers available and menus. The menus in both care homes were available on each table at every meal and offered choices. The residents were however, asked to choose their preferred option the day before if they lived on a nursing unit. Residents in the dementia unit were often able to choose their meal at the time of serving. In Treetops the menu was presented in a plastic stand with the days of the week on the left and the food choices for each day on the right. In Eden Valley the days menu was presented in a black leather wallet (as you may experience in a restaurant).

Despite the different presentation of the menus in the two homes, the staff from both homes felt that they would like to change the way that the menus were presented to make the choices available clearer by; simplifying the menu and using multiple senses such as photographs of the food to facilitate decision-making through enhanced communication.

Four staff in a design focus group in Treetops felt that residents living with dementia were unaware that although the menu only includes two choices, other food items were available on request.

> *CSF21: …sometimes they don't always want what's on the menu, so you can have chips, salad, fish fingers…*
> *CSM5: Yeah but that's for people who can make that choice. So, like [FR name]*
> *CSF4: … say every house… had a board and you could stick things on and like Monday's menu; breakfast, lunch and supper and the main meals are there, but that also goes hand-in-hand there will be a little book there which tells you what they could have like…*
> *CSF21: Like chips or Jacket potatoes*
> *CSF4: … chips or salad and then, you know, the people who are able and capable of making that decision can look through the book and say well actually I quite fancy that.*
> *CSF21: Yeah … cos they're quite good, the kitchen, with doing special requests.*
> *CSF4: Yeah and if we could ... have like a just a board displaying all the kinds of different foods so … you could take the residents to it and they can point to what food they would like…*

In the residents focus group in Eden Valley, the participants discussed how the menus could reflect the activity timetable and include pictures alongside words:

> *ACM03: when I do the activity sheet I put a picture on the sheet along with the activity…I didn't realise that I do it, but I do a picture that represents the activity and that could be a contributing factor why the residents find the activity time sheet easy to read FR023: Yeah… We do have pictures*
> *ACM03: If there was pictures on the menu along with the words FR021 would you find it easier? Like on the activities sheets?*
> *FR021: I suppose I've never tested it, I've just accepted it because it's there … you know. I'm quite sure that if it was there one day and then perhaps the next week it wasn't there then I would realise that it was useful to have that picture there.*
> *RD: So, if ACM03 forgot to put the pictures on the activities one week*
> *FR021: I'd miss it, yes. I probably wouldn't turn up to do it (laughs)*

1:1 Care Staff

As in the dream stage, the idea of having 1:1 care staff to spend time supporting people living with dementia and communication difficulties was widely appealing to staff and family care partners, although it was quickly dismissed by some participants in both homes;

> *CSF62 – That would be lovely but financially that isn't going to happen. (Eden Valley)*

> *CSFN31: …We are here to help them - but just to chat with them, spend time with them so they don't feel alone. I don't like that they feel alone. So to spend time with them and chat, chat, chat, chat. Yes because 1:1 is um, (laughs) a beautiful idea, but is very difficult. (Treetops)*

and combined with dream ideas about activities by others. Care staff in this focus group had the idea of starting 1:1 activities based on their personal choice, and then potentially grouping likeminded people together into small groups

> *CSM6: … give them 1:1 sessions of activities, ask them what they would want to do, and then maybe lots of people choose the same thing and they can do it like that?*
> *CSF22: The ones that have got capacity would feel appreciated that they had been asked individually…I think individually they will say, because in a group some of them might be too shy or too scared to speak up*
> *CSM6: Or all of them are shouting!*
> *CSF22: Or like with MR [name] he won't speak up*
> *CSM6: for example, FR [name], she can do a lot of things, but she doesn't want to go*

None of the participants living with dementia and communication difficulties discussed the idea of 1:1 care staff, even though it was presented to them in the same way as all the other dream ideas. It was not clear if this was because they did not like the idea, found it difficult to envisage or understand, or felt it was impractical.

Man Cave

The idea of a 'man cave' caused excitement in Treetops but moved away from shared decision-making back to what the care staff thought that male residents would like and what they felt would benefit their wellbeing most. The care staff in Treetops felt that this was a good opportunity to create a purpose for the men to go outside. One staff member stayed focused on the residents input throughout;

> *CSF4 – … we could start off small and … if they enjoyed it and get benefit out of it we can add and add and add. I mean for the time being we can just um you know put a table out there and they can look at magazines … you know football or motorbikes or whatever they're into, and then another table where you can have some um old pots*

> *and some just garden spade and forks so they can do some planting on that side just to start it off and see how we went and you know, we could get all that – that's not a problem. But yeah obviously it's all down to them, but I think it'd be nice to have a shed where they could go out and you know… be on their own.*

Food and Drink Options

The food and drink dream ideas were narrowed down and could be categorised into three main areas;

- Having the opportunity to make 'in-the-moment' food choices (rather than pre-ordering)
- ensuring that people living with dementia and communication difficulties were aware that there were additional food choices available
- pureed food

Where ideas about 'in-the-moment decisions' and 'awareness of what was available' were discussed in conjunction with other ideas, the conversation was often positive and energised. There were multiple examples of how the idea of a shop could change the way that people living with dementia made decisions about their food and improve their appetite.

> *CSF 64: … the residents… could just go and pick it up…*
> *CSF 47: Fruit and stuff*
> *CSF31: Fruit and Mars bars or even breakfast cereals …*
> *CSFN01: … And they could have more snacks, even in the room.*
> *CSF47: I can imagine you could even get a lot more people eating that way… because then they have that choice.*
> *CSFN01: and … they can see the choice, how you [CSF31], said about the meals – I cannot make decision because I would like to see. So, if I go and see, I can choose my snack … "I would like this". But if you don't see you don't…*
> *CSF64: sometimes we don't choose by the look of it*
> *ALL: Yeah*
> *RD: Is it about picking something up, smelling it?*
> *CSF64: Yes…if it's fruit…*
> *CSF31: or you feel it don't you?*
> *CSFN01: Not everyone can express exactly "I want apple." (pauses) – "I want something", but like people with dementia they sometimes cannot express exactly*

> *what. They even cannot say that “I am hungry” so they become more agitated... they couldn’t explain to us “I want apple” …maybe they won’t know that apple is what they want until they see. (Eden Valley)*

The care staff were insightful about how complex and challenging even small choices could be but recognised that seeing and feeling objects might stimulate an individual’s desire for that particular item.

Not all the discussions about ‘in-the-moment’ decisions relating to food were so positive. Lots of discussions centred around people living on nursing care units changing their mind when the food arrived. Here, two staff from different types of units in Eden Valley were exploring how to take forward dream ideas around food options. There was a noticeable focus on financial constraints.

> *CSM51: I suppose it’s just economically not viable. It’s just such a shame you can’t make a lot of everything… because we go round on the nursing unit in the morning “Do you want fish and chips or do you want shepherd’s pie?” and so many people, when they get their fish and chips, they probably see “Oh actually that looks nice” and you know, (shrugs and sighs) …We get to know the people who tend to change their mind at the dinner table…*
> *CSF45: … they send up both for us [high needs dementia care unit]. We don’t do ordering, so I’m sure they could send up a bit extra*
> *CSM51: … they’ve just had breakfast and you’re going round saying “Do you want shepherd’s pie?” And half of them don’t know. They’ve just eaten and then like 12.30-12.45 they probably changed their mind… but maybe that’s just how a large home, it works, to some extent.*
> *CSF45: I don’t know, because like I said, on our side we don’t do that because they don’t – so they get the choice, we get 2 mains sent up, and we get finger food sent up. (Eden Valley)*

Both care homes had food available at every meal that was not on the menu (for example; chips, jacket potatoes and omelettes). The care staff were aware of this and so were some of the residents. Through the AI process some of the care staff were keen to make these alternative food options more readily available to residents living with dementia and communication difficulties. An idea about having a board on the wall with pictures of the food choices available had been fielded and discussed in the dream stage in Treetops. In the design stage of the process participants started to give reasons why such dream ideas could not be implemented.

> *CSF4: … unfortunately it's not as easy as going to the kitchen and saying, "they'd like this for dinner", cos you've got to go through and see if they're getting the right vitamins and when it's cooked and how it's cooked. It's a whole new ball game for the kitchen staff and head office and all of that (shakes her head)*

The final category that was repetitively raised and discussed by care staff participants relating to food options was pureed food. This was the only topic in the entire process that was always negative. The pureed diet was considered poor by all the care staff that discussed it from both care homes. None of the resident participants or their care partners raised the subject. Some of the issues about the puree diet were unrelated to decision-making and so are not discussed further here. However, one area was relevant. Several care staff felt that the fact that there was no choice available to people on a pureed diet was unacceptable.

Uniforms

The design of some ideas progressed through multiple iterations; sometimes causing in-depth debate about the purpose and benefit of the idea. Uniforms were discussed in four focus groups and an individual interview in the design stage of the process. This idea caused the most debate of any of the dream ideas that were progressed. A dream idea of dressing up and making things more colourful to stimulate people living with dementia, developed in the design stage to 'dressing down' in ordinary clothes. Some staff had been taught in dementia training that wearing bright colours could be helpful in dementia care:

> *CSF72: Maybe a dress down Friday or something? We could have one Friday a month where we come in, not in uniform…*
> *CSFN01: With the staff… even something with colours, jumper with colours … that we can show ourselves from different side. We are not only nurses, team leaders or carers, we are people also. (Eden Valley)*

Initially this idea did not appear to be directly related to shared decision-making. Some care staff thought that uniforms felt 'institutional' but appreciated the practicalities of uniforms for the purposes of infection control and delivering personal care. However, further discussions about the care staff wearing Christmas jumpers to work in Eden Valley highlighted that some staff and residents thought that the uniforms may represent power and so influence decision-making interactions.

> *CSFN01: … You feel that they, they trust us more. I don't know how to say, but they think about us, not that we are higher because some of them can think that we are higher than them … but when we show that we are on the same level, we are the same people...*
> *RD: So, do you think it would help people to make decisions together because they feel more equal?*
> *All: Yes*
> *CSF64: …there are some residents that …we will go to them and say, "would you like your breakfast?" and they will say "I'm not hungry" and we just like "are you sure you're not hungry? You didn't have much to eat last night" and they are like "oh, just bring me something because you will come with the food anyway" (shrugs) or things like that…*
> *CSF72: and also, lots of the people here are elderly and when they were younger and if you had a uniform, you were in authority, so you did as you were told. So, I still think they think that… if someone had a uniform, you would do what they say so maybe that is why, they think because we have a uniform, they have to do what we say*

Other staff felt that the uniforms were an important aspect of identifying them as care staff. This tied in with the decision field 'who to go to for help', and 'people' as decision-making enablers. The idea of having 'dress down' days was not popular in a focus groups in Treetops;

> *CSF4: I have mixed feelings on that. With our residents here, they know us partly by our uniform … They know that we are here to look after them, they know that we are here to protect them and if they need help. It's our uniform…*

None of the participants living with dementia said that uniforms created a barrier to effective shared decision-making for them personally and some agreed with the staff perspective of it being useful to identify staff.

> *FR023: …they're all friendly and it's like a big (pause) family really*
> *RD: The uniform doesn't cause an issue for you FR023?*
> *FR023: No*
> *FR021: Sometimes it's better to have a uniform so you know who to go to*
> *FR022: Like I've had to this morning, yes (Eden Valley)*

A resident in Treetops said that she liked the idea of staff not wearing uniforms because she thought that it was fun and although she understood that uniforms may have an impact on the feeling of equality for some residents, that did not apply to her;

> *FR350: … within reason, I do what I want! (laughs) "No, I'm not doing that!" But they're very good, they don't try and do power struggles with me.*

Communication Aids and Going Out more

The ideas around communication aids and people living with dementia going out more ceased to exist as independent entities in the design stage. They were both integrated with other dream ideas about menus, the food offer and the post office/shop.

Residents Meeting

The idea of a residents meeting gained traction in the design stage with 17 conversations about it in four interviews and two focus groups, all in Treetops. Family care partners thought that residents having an input into the management of the home was a good idea, if the resident was able to participate;

> *FRF21: Well, I think that's very good if somebody, umm, hasn't got dementia, but then mum was gonna get up this morning and walk* ***– walk*** *- to see me, wasn't you?*
> *FR21: (Nods and smiles) mmm*
> *FRF21: So, er, I think yeah, that's good for maybe a different ward... Yes, definitely, but not for everybody.*

Some care staff in Treetops were positive about the idea of a residents meeting but concerned that some people living with dementia would not understand the purpose and offered ideas of how to support them using multiple senses;

> *CSM5: it's a good idea, the meeting for the residents so they could er, say what they what would they like.*
> *CSF6: yeah it depends if they will understand what they are talking about so maybe will help here with video and pictures again.*
> *CSM5: I don't know if they can decide*
> *CSF6: maybe they will not understand the word as well 'meeting' what that means for them. Maybe you can just ask them … "do you want to go to talk about your life" or "what you like here and what you don't like"*

Another member of staff appeared to process the idea as she was talking. She described how the staff advocated for the residents living with dementia, and then realised that their perspective as residents may be very different from her view as a member of staff:

> *CSFN31: Well, it's a good idea because they are here and they, they have to choose if they like or not, or if they like to complaint, but not every resident are able to do it because the person who has dementia maybe one day can go and maybe the next month maybe not…*
> *RD: Do you think that [some residents] would speak up on behalf of the people who are less able?*
> *CSFN31: Well, I think that we are doing, the staff. But they could do as well because they have different points of view. And I think this is very good because, if she's happy or not is very important. Because I think she is happy because I am doing something, and she's (pause) not! (laughs). And it's very interesting to know. To have a discussion, a good discussion not a bad discussion, to improve everything. Oh yes. I like it!*

Conclusion of the Design Stage

During the design stage of the process it became clear that there were key factors and processes that enabled ideas to progress:

- Ideas grounded in participant stories appeared to appeal more widely and gain traction more easily.
- Ideas that had at least one person championing their cause were discussed more frequently and in more depth. The role (or seniority) of the champion appeared to have no bearing on this.
- Participants were outcome focused; with the outcome being resident experience, rather than the implementation of an idea itself.
- Care staff participants readily offered to take an active role in driving forward ideas that they believed could have a positive impact on care delivery. This included coming into work on their days off and raising money for resources.
- More design progress was made in focus groups than in interviews.

Destiny Stage

A series of final interviews and focus groups followed-up the design ideas that had been discussed and progressed (or not). In some instances, the ideas had developed through multiple iterations and then stalled late in the AI process. At the end of the design stage of the 4D cycle seven of the original 17 dream idea categories remained, although not in their original state. Six of these ideas (86 per cent) were based around participant stories (marked with an asterisk).

- Post office, shop or village*
- 1 to 1 care staff*
- Food and drink options*
- Menus*
- Man cave*
- Uniforms*
- Residents meeting

Participants were asked if anything had changed since we last met. This was an invitation for them to talk about changes in the residents or staff, their living or working environment and/or the care home generally. Whilst many of them did take the opportunity to chat, they also quickly started talking about changes that had, and had not, been implemented as a result of the AI.

No ideas were fully implemented as they were initially dreamed and designed in the destiny stage of the 4D cycle. The ideas therefore fell within the categories of;

- not implemented
- partially implemented

Ideas were considered not to have been implemented where there was no outcome by the end of the final observations that followed the destiny interviews and focus groups. Ideas were considered to have been partially implemented if they;

- fulfilled the remit of their original purpose but no longer resembled the original dream or design, or
- were no longer directly related to their original purpose but remained relevant to shared decision-making.

None of the ideas that were identified in the dream stage and then progressed through to the design stage were implemented in full as they were originally ’dreamed’, regardless of the number of participants involved or how meticulous or detailed the design process had been.

Ideas Not Implemented

Uniforms

The ideas about uniform appeared to have lost traction and were not really discussed in the destiny stage. This was the only design area where there had been no progress and none of the participants appeared to have any concern or regret about it.

Man Cave

In the destiny stage of the AI process the idea of a ‘man cave’ was discussed by a total of six care staff in two focus groups in Treetops. Shared decisions about its design had been advocated throughout the 4D cycle by two of the care staff who discussed it in the final stage. The two staff were in different focus groups and both had different perspectives on the progress of the idea;

> *CSF4: (points outside) that shed’s gonna turn into a man cave for the men to go out there and chill out and do whatever men do. As soon as the nice weather’s here and we can get things rolling. We’ve got a garage up the road here where we can get some old car parts and we’re gonna get some magazines. [Manager]’s all for it and he’s prepared to go and pick things up and he will help in whatever way. But obviously, weather wise, we can’t do nothing until the better weather comes*
> *RD: that’s definitely going to happen?*
> *CSF4: Absolutely. 100 per cent. Yeah, yeah, yeah!*

This member of staff had clearly discussed the idea with the care home manager and planned to progress the idea when the weather improved. The other leading advocate for the idea had consulted the male residents and fed back the results to focus group participants;

> *CSM5: Oh, and the one thing, we won’t manage to do that - turn the shed into man cave (screws up face and shrugs)*
> *RD: you don’t think so? Why not?*
> *CSM5: cos I went round and asked them what they want to do and they were all different. And some of them didn’t want to do anything, so… That’s the problem so I don’t think we can manage to do that…*
> *RD: …can you tell me more about what they said when you asked?*
> *CSM5: well MR [name] he said he didn’t want anything and (shrugs)…*
> *CSF 22: Yeah, well, I think he’s quite depressed*
> *All: (Agree)*

> *CSM5: he doesn't want to do anything*
>
> *CSM6: yes, he is angry all the time*
>
> *CSM5: MR [name] said he wanted to go to the pub and have a lager… I don't think they want to do any manual things*
>
> *CSF22: well then you could turn it into erm…I don't know. You could go and have a nice drink out there, or have a TV out there to watch football*
>
> *CSM6: that's what I said… MR [name] will like that I think*

As a result, he could not see a way to progress the idea whilst fulfilling all the residents' requests. In addition, he seemed disappointed that some of the residents living with dementia did not want to do anything.

Ideas Partially Implemented

Each dream idea evolved from multiple observations and stories and each progressed in a different way. The example of the village post office or shop is explored in more detail below to highlight the complexity of how developing ideas evolved through the AI process.

Menus and Food and Drink Options

Participants in both homes had wanted to change the way that the menus were presented and had made comprehensive plans about how they would implement their ideas during the design stage. In both homes they planned to have an example of the food plated in the kitchen as the chefs would like it presented. The kitchen staff would then take photographs of the food and these were to be added to the menus. In Treetops they also wanted to simplify the menus for people living with dementia by displaying only that day's food choices.

These ideas were not implemented in either care home. However, unlike the ideas about uniform, there appeared to be widespread regret that these ideas had not been taken forward. This was discussed in four focus groups and one interview in the destiny stage.

> *RD: The pictures on the menus, I understand the person that was going to take that forward has left.*
>
> *CSF45: Mm gone… Nothing's happened at the moment but [chef's name] is in the kitchen now and he's really, really good… and he actually came up to the unit the other day, cos he come round to have a chat and I did mention to him about the menus and he said he is going to try and get something in place. It might take a little*

> *while, but he is actually going to try and change them... (Eden Valley)*
>
> *CSFN01: Do you remember when we spoke about those pictures? About to serve meals. I was quite disappointed that this hasn't been done yet.*
> *CSF64: They have done a few. We had a problem with one of the chefs, but they have started already. (Eden Valley)*
>
> *CSFN31: … I didn't have time to say to [manager] to suggest … about our last conversation [the menus] because many time when I am here [manager] is really busy so I didn't do it. But I didn't forget it. (Treetops)*

Reasons given for the ideas stalling related to changes in staffing and the wider food offer (one of the homes was said to be moving towards 'fine dining'). All the care staff participants that talked about the menus remained committed to the idea and five of them thought that it would happen in the future.

> *CSM 5: … pictures on the menus that would be brilliant and daily menu…yeah*
> *CSM 5: Yes, to have that and to keep what we've got now because some people are capable. They can read ahead to see what's on Thursday and Friday*
> *CSF 22: Yes, the one that we've got has got [every day] and they sit there and say "what's today?" … so, you give them … one with today's date on it and todays food with a picture of the choice. Yes, it would be less confusing for them*
> *CSM 6: for all the units*
> *CSF 22: Yes, cos there's quite a few residents on each unit … that have got dementia*
> *RD: so, you still like the idea [of pictures on the menu] but there's no progress with that at the moment*
> *All: no (Treetops)*

Although these ideas had not been implemented in the way that it had been dreamed and designed, there had been changes that had affected resident experience associated with food related shared decision-making in both homes.

During the dream stage of the 4D cycle a care staff participant in Eden Valley told a story, in a focus group of eight care staff, about a gentleman living with dementia who liked to see the food on a plate before he chose which meal to have. This story was shared with interview and focus group participants in both care homes and was partially responsible for the dream idea of photographs of food being added to the menus. Although the menus in the care homes had not changed prior to the end of the study, the practice of plating alternative food choices appeared to be more commonplace on the dementia care units in Eden Valley. The practice of plating food choices facilitated shared decisions by stimulating multiple senses, (including sight and smell,) which was one of the most effective everyday decision-making enabling factors identified in the discovery stage of the 4D cycle.

A change in Treetops was related to the simplification of the menus. The idea of having a board on the wall in the dining room or corridor displaying food and drink options for people living with dementia was designed in Treetops to support increased choices and communication. Again, the change in practice was entirely different from the ideas that had been dreamt or designed, however it facilitated decision-making for the people living with dementia on the unit in which it was implemented. The member of staff who had originally fielded the idea was from a nursing unit;

> *CSF 21: [unit name] we've now got a notice board in the dining room with the date on, what activity in the morning and we rub that off and put what activity in the afternoon…but we don't put menu's on. We put the date, what's going on and…*
> *CSF 6: And how the day is outside…It's nice I saw it on Tuesday*
> *CSF 21: So, we've got a notice board now so that's nice. You have to be careful what you put on or it would be too busy …and sometimes we put, (pause) let me give you an example "smile and the world smiles with you" – something every day… so that's changed.*

The care staff participant acknowledged that that the board was not being used as a choice facilitator as was originally planned. However, the notice board fulfilled the role of an environmental and communication enabling factor to support shared decision-making by visually reinforcing information that could be referred to as a reminder. In this way it partially fulfilled the idea about simplifying the menus by acting as a reminder of the day of the week for people living with dementia.

Post Office, Shop or Village

Possibly the grandest plan from the dream stage of the 4D cycle was the idea of have a village, shop or post office in the grounds of Eden Valley. Some of the care staff remained committed to the idea throughout the design stage and this was supported by resident participants who were also keen on the idea.

The idea of a dementia friendly village, shop or post office in the grounds of the care home was initiated in a dream focus group where staff were discussing feedback from observations and telling stories about residents' shopping and their desire to access and spend money. This example is from a focus group in Eden Valley:

> *CSF 65: They are always going … – the residents – "I need to go to the bank, I need to go to the bank" …and I'm like "so and so, it's 5 o'clock. It's shut now". He's like "oh but I need to go into town, I need to go to the bank" and I'm like "don't worry we'll sort it out, I'll speak to your wife and she can sort all your bills out. You don't need to worry about anything" but he's determined he needs to go to the bank.*
> *CSF45: …They get really obsessed with it don't they? Money. Thinking they need to have to pay for something.*
> *CSF65 – It's just like giving them even like money that's not real – so they could go into that shop and like pay for it. So at least they think they've paid for it so they can be satisfied in a way. Cos some people you say "oh no it's alright, it's on the house" or "you don't need to, it's been paid for" and they'll be like "no" – they won't accept it, but if you gave them like their own money so they can – "oh I'm going to the post office" and can buy some stamps or whatever…*

Residents and family care partners also told stories about shopping trips:

> *FRF21: …We do go out, not so much round the shops now do we? But yes, it's a long time for a decision as you can imagine.*
> *RD: …can you think of an example of when you made a decision together…?*
> *FRF21: (nudges FR21 and smiles) When we went and got the jumpers.*
> *FR21: Oh yes, ha-ha. We got some jumpers!*
> *FRF21: At the garden centre, wasn't it?*
> *FR21: At the garden centre, yeah.*
> *RD: Can you tell me about that? What made you decide to get those jumpers?*
> *FR21: They looked nice that was why. Looked nice and their colour wasn't too lary it was just a quiet colour…Ummm. Most had white backgrounds, didn't they? (FRF21 gestures to the jumper that FR21 is wearing and nods. FR21 laughs and points to her jumper). Those two yeah. (Treetops)*

Participants combined feedback about shopping and money with examples of residents' sensory needs to see, smell and touch food to help them make choices and decisions.

> *CSF45: We have three separate lots of food come up at lunch and 2 at supper and we actually plate them up, and we take them, and we show them - the ones that we know that can't make the decision on what they want. We will show them each*

> *plated, and they will pick which one they want.*
> *RD: You would actually plate the food and then show it to them?*
> *CSF45 – Yeah…For the ones that really can't get across what it is they want. We will plate it up - because we always have loads - we will plate it and then… they will choose which one they want. And the same with the juice. We'll make up 3 different squashes and …they will point to which one they want. (High needs dementia care unit - Eden Valley)*

The idea of the post office or shop was discussed in twelve dream and design focus groups across both care homes; including the residents' focus group. Staff stated that they thought that a shop would improve residents' wellbeing by enabling shared decision-making through supporting people to spend money on food and personal care items, whilst engaging them in physical activity by giving them a purpose to go outside. Participants were not disconcerted by the size and complexity of the project; instead they discussed the potential advantages for the residents:

> *CSF45 – The benefit would be that people would, you know the residents, would feel … empowered. Just by the fact that, you know, they – to them in their minds – they're going* ***into*** *a shop, and they're actually (pause), they've got a choice. Even though we give them choice, there's actually* ***stuff*** *there.*
> *CSF 65 – and they just pick and… they just pay it and they feel "oh, I feel good" …*

The care staff in Eden Valley were clear that the main purpose of the post office or shop was to empower the residents. They wanted to create opportunities to; spend money, make choices and motivate people to go outside. In addition, they felt that a shop would position residents as capable by tailoring the environment to maximise time and sensory possibilities to enable their participation in decision-making. Following a design focus groups, a staff participant fed back the idea of the post office, and more specifically the post box to the clinical lead in Eden Valley. The member of staff had told her about how excited all the participants had become at the prospect of enhancing written communication between the residents and their families. The clinical lead thought that the idea had merit and decided to look for a post box that residents (and family care partners) could use when mailing letters.

At my next visit, the clinical lead explained that she had purchased and installed a vintage, George VI, post box (see Figure 10). The clinical lead said that she selected the box because, not only was it beautiful, it was from an era that many of the residents might remember and be able to relate to. The residents and care partners could post their mail and that it would be emptied daily (and franked if necessary). The installation of the post box appeared to represent the ‘success’ of the AI for some staff in Eden Valley. When asked if anything had changed since we had last met a participant told me;

> *CSF47… we got a post box! It’s downstairs… not only that, but the tuck shop is in progress at the minute.*

Figure 10: The Post Box Installed in Eden Valley Care Home

The post box was placed in the main entrance of the care home between the front doors and the reception desk. Some of the staff thought that the post box was there as a Christmas ornament and were unaware that it was a permanent fixture. Other staff told me that some residents were regularly using the post box. A care partner told me in passing that it ‘was a godsend’ because she was able to post her letters and bills without having to go all the way into town before visiting her husband.

One member of staff who had been a strong advocate of the idea of a post office from the outset of the AI, finished the process with a story. In telling the story she repeated that the gentleman that she was referring to ‘was proud of himself’ several times, seemingly to reiterate how important the act of visiting the post box had been for him. She was tearful as she told the story;

> *CSF47: MR [name] … said “I want to go to the post box” so I took him downstairs to the post box and he goes “oh thanks” and just put a plain bit of paper in there.*

> *(pause). I was like (shrugs and looks sad), but now he hasn't mentioned about going to the post office (frowns). It's amazing!*
>
> *RD: So, you took him down there and he put a piece of paper in?*
>
> *CSF47: And he was* ***really*** *happy! He was* ***really*** *proud of himself! And it was just that* ***effort****. Cos he does get really tired cos of his Parkinson's, cos it's progressing now, and he goes, "I'm really tired now" … and he was really proud of himself…*

This story suggests that the post box was an important environmental factor for this resident although the remit of increasing everyday shared decision-making for multiple residents through the creation of opportunities was largely lost.

There were also concrete plans in place for the trolley shop but many of the care staff did not feel that this fully realised their vision for increased opportunities for shared decision-making.

> *CSF 45: It's not the same! it's like a hospital - it's not the same.*
>
> *CSF 65: It's like 'trolley dolly' (frowns)*
>
> *CSF 45: … surely part of our job is to get our residents off of the unit; out into a little bit of fresh air.*
>
> *CSF 71: to promote a little bit of independence.*
>
> *CSF 45: yeah… a little bit of independence.*

The decision to install the post box was a direct result of the AI process. However, it was implemented early in the AI process before all participants had a chance to revisit, test and develop the idea to its natural conclusion. In this way, individual voices were lost from the idea, over-ridden by well-intention organisational decision-making.

1:1 Care Staff

One of the most popular dream ideas was to have 1:1 care staff available for everyone living with dementia and communication difficulties. In Treetops the participants had combined this idea with those about activities in the design stage of the 4D cycle. The idea was implemented in Treetops although it was not clear if this was due to the AI process or to the employment of a new activity coordinator who had previously worked in learning disability services as well as in Treetops. She was keen to extend the activities in line with what the residents and their family care partners presented as wanted and needed in the home. The care home manager was instrumental in that he empowered the staff member and gave her autonomy to act in the way that she perceived to be most beneficial to the residents.

In their final interviews and focus groups, four of the care staff, a family care partner and a resident talked about the 1:1 activities in the home;

> *CSF 6: … and something else changed. ACF4 is doing now activities and she will come and she will do 1 by 1 activities with our residents… This is a big change for us… For example, ACF4 is coming to do with MR [name] some painting. And she's coming another day she said. And she will take MR 10 out for a walk…*
> *CSF 4: Just for [dementia units] at the moment*
> *CSF 6: because the other units can enjoy the other activities…*
> *CSF 21: Yes, that's just started. Everybody with dementia will get a 1:1 …that's what we've been told*

Residents Meeting

The original idea of a residents meeting with the care home manager was not implemented in Treetops. However, in addition to the new 1:1 activities, a meeting was convened by the new activities co-ordinator giving residents the opportunity to share in the decisions about what should be included in the organised activities programme. This led to one resident in particular having a greater input into the programme and increasing activities that more people enjoyed and reducing those that were less well attended.

Conclusion of the Destiny Stage of the Process

Five of the seven ideas that progressed to the destiny stage of the process achieved an outcome that had the potential to make a positive impact on shared everyday decision-making between people living with and their staff and family care partners in these two care homes. Changes that were implemented were managed and led from within each home with no input from me (other than facilitating the AI process). Participants demonstrated a sense of genuine joy and accomplishment associated with some of the interventions, and disappointment in some of the areas that were not fully achieved.

Summary of key findings

The key findings in this chapter related to; shared everyday decision-making for people living with dementia and communication difficulties, and the AI process. The care home management team were regularly referred to throughout the process and had the power to facilitate or hamper the progress of ideas. However, in both these care homes, it appeared that the participants had been given the authority to implement developments that were perceived to improve shared everyday decision-making practice for people living with dementia. The participants themselves reshaped plans when they became too costly in terms of time or resources.

Shared Decision-Making

People living with moderate to advanced dementia and communication difficulties wanted (and were able to) participate in decisions about their everyday life and care in the care homes, although participants perception and understanding of what shared decision-making entailed differed, and that appeared to influence the AI process. For example, ‘meet the chef’ meetings, giving residents and their staff and family care partners the opportunity to discuss the food offer in Treetops, were not recognised as being related to shared everyday decision-making by the care staff or resident participants.

Prior to the commencement of this study there appeared to be a relatively high level of democracy in both care homes, and participants may have felt empowered and had the autonomy to participate in everyday shared decision-making with, or without, this AI process. All the ideas implemented were able to promote shared everyday decision-making in one or more of the fields, and through all the enabling factors, identified in the discovery stage.

Appreciative Inquiry 4D Cycle

Almost everyone living with dementia and communication difficulties was able to participate in the AI process in some way, although they appeared to find the abstract nature of the dream stage challenging. Dream ideas that stemmed from, or were related to, participant stories were most likely to be progressed through the 4D cycle; the role of the storyteller appeared to be immaterial. Almost one third (29 per cent) of the original dream ideas resulted in a resident focused outcome. These outcomes were all facilitated through the AI process, but did not necessarily follow the 4D cycle in the way that it is presented in the literature. Ideas that had one or more strong participant champions were also more likely to progress.

Participants enjoyed the AI process and appeared to appreciate my facilitation style. There was lots of laughter and recognition of the importance of what they do each day. Care staff valued the opportunity to have the time and a creative space to share and develop ideas that could impact on the day to day life of everyone in the care home. Three care staff in Treetops shared their thoughts on the AI experience, and reiterated what was important to them:

> *RD: … you feel like there has been some positive change…Do you feel that any of the changes are related to this [AI] process?*
> *All: Yes!*
> *CSF6: …we are more a team, we can talk a lot about it and then one of us can go to [manager] and say, "we would like to have this, we would like to do this", and he would say yes for everything*
> *CSF21: he would say yes*
> *RD: So, is it hard to get the opportunity to [get together]?*
> *CSF21: It's difficult because of staffing levels and long days and lunch breaks and breaks, it's lovely you coming, and sometimes it's not always easy.*
> *RD: I do appreciate how much effort you all make to come to these groups.*
> *CSF4: I think because you're here you are giving us, a*
> *CSF6: a push*
> *CSF4: a reason to be here [in the focus group], if that makes sense… we are here to make life better for them, not us…Don't get me wrong, we all have days when we are tired, and our feet hurt, and we want to go home, but I can honestly personally say that 99 per cent of the staff here go home knowing they've done their best*

The developments in both care homes were implemented by the participants through a collaborative appreciative process with only 'light touch' external facilitation from me. The relatively diverse groups of participants were able to recognise the good in themselves, each other and their care homes.

Chapter 6 - Discussion

Introduction

This study followed a systematic review of the evidence with an Appreciative Inquiry (AI) to understand what people living with dementia and communication difficulties and their staff and family care partners perceive as good practice in shared everyday decision-making. Specifically, the study sought to:

- Understand what the key everyday decisions are that people living with dementia and communication difficulties make and share with their staff and family care partners in care homes.
- Explore opportunities for shared everyday decision-making and how they are understood and facilitated, by people living with dementia and communication difficulties, and their staff and family care partners in care homes.
- Use participants stories and experiences of shared everyday decision-making in care homes to facilitate and share current positive practice through AI.

In this chapter I discuss the extent to which the key findings from the study answer the research questions. I consider the differences between decision-making and choice and draw together the implications of both phases of the study to identify how people living with dementia make and share the everyday decisions with their staff and family care partners in care homes. This is discussed in the context of decisional capacity and communal living. The usefulness of an appreciative approach in answering questions about shared everyday decision-making in care homes is also critically examined. Reflections on lessons learned include the impact of my role as an experienced clinician and 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 systematic review (Daly et al., 2018), included 19 studies exploring, or relevant to, shared everyday decision-making in extended care environments. The review demonstrated a lack of relevant evidence especially including the voices of people living with dementia and those living in extended care environments. It found a lack of consistency in the definition of shared decision-making for people living with dementia and highlighted that people value the opportunity to participate in decisions about their life and care. It also established that limited tools or resources have been developed, tested and validated to embed shared everyday decision-making in the context of care homes.

The AI involved 15 people living with dementia and communication difficulties, 24 care staff and four family care partners. As a process, AI was acceptable to all groups of participants. People living with dementia and communication difficulties were able to engage in the AI process when it was adapted to meet their individual needs and to facilitate personal expression. They appeared to enjoy the process, and care staff appreciated the time and space to create and develop ideas together. Unlike studies that have reported difficulties in maintaining momentum (see for example, Bushe, 2011, Reed, 2010), engagement was sustained over the entire nine-month period of the study. Following the 4D cycle of AI; observations, interviews, focus groups and storytelling were used to involve participants and to understand their experiences of shared everyday decision-making in the environmental context associated with each care home. The participants used their understanding and experiences to ‘dream’ of ways to enhance their shared everyday decision-making practice even further. The dream ideas were either discarded or developed by the participants into five implemented strategies: A post box, an information board, 1:1 activities, a residents meeting and presentation of food choices. Ideas that resulted in an intervention were likely to; have been based on a participant story and have a strong advocate. Participants reviewed, changed and shaped ideas through to implementation but not in the way that it is typically presented in the AI literature.

Discovery stage

Defining Shared Everyday Decision-Making with People Living with Dementia

Evidence suggests that decision-making is the product of two distinct systems of reasoning: a rule-based conscious and deliberate system, and an associative, subconscious, impulsive system that is sensory-driven (Sloman and Hagmayer, 2006, Thaler and Sunstein, 2008). Everyday decisions are often more likely to fall into this second, more intuitive, category; being required numerous times during any given day and rooted in daily routines and conversations (Boyle, 2014, Samsi and Manthorpe, 2013). Despite the subconscious nature of many everyday decisions, they are often composite in nature and necessitate complex cognitive processes requiring a judgement related to a choice (Sinz et al., 2008).

The term ‘shared decision-making’ in relation to dementia lacks specificity and universality in its use (Bhatt et al., 2018). For example, the term has been used to describe everything from a dynamic interactive process including the person living with dementia, to decisions made by staff and family care partners *for* people living with dementia without their active participation (Horton-Deutsch et al., 2007, Smebye et al., 2012, Tyrrell et al., 2006). The extent to which the individual living with dementia is involved, is therefore often unclear. This study recognised that at times, the boundaries between levels or types of involvement in everyday decisions were blurred and difficult to measure.

Previous studies suggest that the level of participation in the decision-making process is less important to the person living with dementia than the act of involvement (see for example, Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Horton-Deutsch et al., 2007, Tyrrell et al., 2006). This was mirrored in my study. In Table 18 the example of a member of care staff tasked with clearing and tidying a resident’s room following a risk assessment, suggests that the resident’s involvement was minimal; however, the *act* of involvement was reported as stopping her ‘panicking’ and ‘swearing’ and made her ‘more happy’. The staff member directly attributed the resident’s behaviour and mood to her ‘participation’ in deciding where her belongings were moved to.

Shared everyday decision-making in the context of dementia care may not always reflect what is typically understood by the term in its clinical sense (Durand et al., 2014, Elwyn et al., 2006, Issues., 2011). However, in the care homes in this study shared decision-making with people living with dementia did rely on including the same key concepts as in the wider community; the persons values or preferences, available information and recognising certain contextual limitations. These in turn, relied on care staff knowing and understanding the person – for example, an ability to interpret their mood and responses based on often long and intimate associations in addition to the more widely recognised biographical information collected about past and/or current values.

Simple choices, for example around drinks, often required multifaceted and compound decisions – would the person like a drink? Would the drink be hot or cold, what type of hot drink, did the resident require sugar and/or milk, and would they like a biscuit to accompany the drink? This is an example of a relatively common decision where the care staff could have predicted the answers to many of the questions but were careful to take the opportunities to enable residents to make choices and decisions so that they could maintain a degree of control. Care staff actively used encouragement, visual aids and prompts as well as contextual information to support people's involvement in these decisions. For example, a member of staff encouraged a resident who wanted to go outside for a cigarette to put on a pair of socks because it was snowing; she then took him to the window and showed him. As an observer, this method of conveying and validating information appeared to enhance positive communication and result in the resident making a 'shared-decision' to wear socks. However, there is limited empirical evidence examining what constitutes 'good' verbal and non-verbal communication from the perspective of people living with dementia and communication difficulties (Alsawy et al., 2017, Cameron et al., 2018, Machiels et al., 2017) and how that impacts on their decision-making involvement.

Twenty different types of everyday decisions were made by and with people living with dementia in the care homes. The most common were related to food and drink, personal care and organised activities. When a decision involved binary choices - yes or no - the extent to which this could be interpreted as shared decision-making is debateable. For participants however, (particularly residents and care staff) these were important examples that recognised and affirmed the individual and their right to decide on everyday details of their daily life. Previous work centring on the recognition and inclusion of and connection with people living in care homes supports the findings that people living with dementia choose to include themselves in those conversations (Owen et al., 2012).

The majority of decisions I observed were shared inasmuch as they relied on a response from the person living with dementia. This reflected the findings of the systematic review completed in Phase 1 of the study (see for example, Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Godwin, 2014, Horton-Deutsch et al., 2007, Tyrrell et al., 2006). However, many other decisions were perceived by all parties to be independent; albeit within the physical, social and biological constraints associated with communal dementia care. Data from this study demonstrated that staff engaged with the idea of shared everyday decision-making, it fitted with the person-centred ethos that appeared to be embedded in both care homes, and emphasised equality and resident engagement, which further aligned results with previous work (Owen et al., 2012).

It was clear that participants' understanding of what constituted shared decision-making varied and the terms 'decision' and 'choice' were used interchangeably. This influenced the ideas generated in the AI process with care staff giving more attention to increasing available choices than identifying ways of creating opportunities for residents to initiate decision-making. It was therefore useful to understand if the residents living with dementia were participating in decision-making or simply expressing choice. A decision involves making a judgement about something whereas a choice is the opportunity to choose between things[7]. Therefore, to make a decision, an individual must have an awareness of the choices that are available, the consequences and importantly, any boundaries in place.

Decision-Making or Expressing a Choice

Effective decision-making comes from a place of choice (Nichols, 2004), and care staff in this study appeared to embrace that. Care staff appeared to appreciate that choice was an essential precursor to decision-making but offered conflicting perspectives on how it could and should be used to promote shared decision-making for people living with dementia. Some care staff felt that simplifying choices reduced the cognitive strain whilst promoting an element of control. Other staff offered whatever was available, arguing that 'limiting options' was 'taking away' choice. As a result, residents (including people living with more advanced dementia and communication difficulties) were regularly being offered choices and making decisions, albeit within social, environmental and resource constraints associated with communal living recognised by Godwin (2014), and Kjellberg (2002).

The DEEP Dementia Voices Network engages and empowers people living with dementia to influence attitudes, services and policies that affect their lives (https://www.dementiavoices.org.uk/). The Dementia Action Alliance (2019) have produced five statements that align with freedom of choice:

- We have the right to be ourselves.
- We have the right to carry on with day-to-day and family life.
- We have the right to quickly find out about medical problems or diseases.

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[7] Definitions taken from the Oxford English Dictionary

- We have the right to be respected.
- If we want to, we have the right to take part in dementia research.

However, care homes are largely deterministic environments, where residents behaviour (and choices) are influenced by either social, biological or environmental factors (Martin and Sugarman, 2002, Skinner, 1971).

Although care staff were willing and able to share decisions with residents, deterministic environmental and organisational constraints often meant that the management and/or staff member remained largely in control of the choices that were available. The systematic review highlighted that opportunities for people living with a cognitive impairment to express choice diminished as their daily care needs increased in care homes (Godwin, 2014, Kjellberg, 2002), although the reduced opportunities were not always directly related to their cognitive impairment. The interviews and focus groups corroborated observational data in this AI study, identifying that the biological effects of dementia and communication difficulties sometimes had equally deterministic effects on decision-making. Fluctuating mental capacity and the nature of the care home environments further limited choices available to residents increasing these deterministic effects. For example, meals are served at specific times. Some residents in this study were able to mitigate limitations by deciding to save their main meal until the evening or not to have what was on the menu. However, people living with more advanced dementia were not able to access these choices because they were not aware that they existed.

Despite a lack of consensus about how decision-making is shared and understood by, with and for people living with dementia in an everyday, non-clinical context (Bhatt et al., 2018, Daly et al., 2018, Davis et al., 2017), it is recognised as becoming more complex for older people with multiple health and care needs. Decision-making capacity and support networks diminish (Bunn et al., 2018a). It remains an ethical imperative and an essential of person-centred care (Coulter and Collins, 2011, Edvardsson et al., 2014a, Edvardsson et al., 2008, Mccance and Mccormack, 2017).

On the basis of evidence emerging from this study combined with other recent studies (Bhatt et al., 2018, Bunn et al., 2018a, Fetherstonhaugh et al., 2016, Harrison-Dening et al., 2017, Mariani et al., 2016, Miller et al., 2016), I would suggest that shared everyday decision-making in relation to dementia care[8] could be conceptualised as;

> ‘a person living with dementia and their staff and/or family care partner being aware of the everyday care options and using the available information to mutually contribute to an overall decisional outcome’.

This definition acknowledges interdependence in everyday decision-making in dementia care and accepts the fluctuating nature of decisional capacity and the potential impact of multiple care relationships in long term care settings. In any definition it is important to accept that decisional ability is neither linear nor absolute in the context of dementia and that it may fluctuate between autonomy and varied levels of support required (Davis 2017; Samsi and Manthorpe 2013).

Quality of Life

The Quality of Life in Alzheimer’s Disease (QOL-AD) assessment tool (Logsdon et al., 1999) was not used to capture the before and after quality of life data as proposed. However, it did provide some interesting data prior to the AI interventions. More than half the participants living with dementia, scored their own quality of life higher than their informant; a finding that contradicts that of the tool developer, but reflects research proposing that people living with dementia have a more positive perception of their own quality of life than their staff or family care partners (Selai, 2001, Spector and Orrell, 2006, Thorgrimsen et al., 2003). This emphasises the need to involve people living with dementia in everyday decision-making about their life and care and demonstrates the differences in quality of life related priorities and perceptions.

The before and after quality of life assessment was retracted due to some participants becoming distressed by the words ‘dementia’ and ‘Alzheimer’s’ used in the tool. Interestingly this included people both with and without a formal dementia diagnosis. This reflects the persistent stigmatising nature of these words and the reluctance of people to be defined in this way (Dementia Action Alliance, 2019), even in a care home environment. Stigma associated with dementia can be internal ‘self-

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[8] This specifically in relation to dementia care and does not necessarily reflect SDM in the wider dementia community as it uses the term ‘care partner’ and so assumes a level of inter/dependence.

stigma', as well as social stigma, and is understood to extend to family care partners (Garand et al., 2009, Watson et al., 2007). The inability and/or reluctance of participants to complete the QOL-AD, supports concerns regarding the acceptability of the tool for those with more advanced dementia (Bowling et al., 2015). For spousal care partners, this may also be associated with 'intrusive' questions highlighting how their 'couplehood' had changed (Sinclair et al., 2018).

Decisional Capacity

Despite an increased awareness of the MCA and its application in practice (Manthorpe et al., 2011), its interpretation and operationalisation beyond decisions about significant events (such as preferred place of death), is not well documented. The historical assumption that people living with dementia cannot participate in decision-making has caused considerable debate (Dresser, 1995, Dworkin, 1993, Jaworska, 1999), largely in relation to respecting precedent autonomy. This study found that people living with advanced dementia were still involved in some everyday decisions about how their care is planned, delivered and received. They also developed new preferences and changed their mind if accommodated to do so by staff and family care partners. This adds to the growing body of knowledge demonstrating that people with moderate to advanced dementia can reliably report on their values and preferences in relation to their care and well-being (Boyle, 2014, Feinberg and Whitlatch, 2002, Whitlatch et al., 2005). Care staff in this study were attuned to people's preferences and aware that their choices might change. For example, on page 108 CSF4 believed that she knew what a resident would like. However, she was careful not to be "complacent" about the choices or decisions that they might make. Experience and awareness of changes in residents' capacity appeared to be more helpful to them than measures, in enacting legislative frameworks such as the MCA (2005). This has implications for the way that dementia diagnoses and biographical information is shared, documented and used by health and social care professionals to best support and care for people living with dementia. For example, when care staff knew a person well, they demonstrated expertise in understanding how fluctuating capacity could be accommodated but were unsure how that could be effectively documented in a resident's daily care record.

The people living with dementia who were least involved in their everyday decision-making in this study were those who were, or were perceived to be, unable to participate due to the effects of advanced dementia. These findings reflect those of Samsi and Manthorpe (2013) and Smebye et al. (2012) who highlighted that exclusion from the decision-making process was predominantly caused by *perception* of inability and incapacity. My observations from high needs dementia care units, identified that people living with the most advanced dementia and severe communication difficulties were being ‘included’ in decision-making by staff and family care partners describing the choices available and then explaining their own thought process in decision-making. The staff and family care partners vocalised the process for the resident’s benefit; any behavioural response was then taken into consideration and acted on accordingly.

Investigation and interpretation of individual’s often subtle non-verbal and para-verbal communication requires skill and can be extended using psychosocial approaches such as those advocated by Kitwood (Cameron et al., 2018, Seidl et al., 2011). The study found that family care partners were often comfortable making sense of resident’s behaviours presuming they knew the resident’s needs and wishes. This was said to be based on the length and strength of their relationship and again mirrors prior research findings (Hirschman et al., 2005, Horton-Deutsch et al., 2007, Samsi and Manthorpe, 2013, Tyrrell et al., 2006). In contrast, the care staff in my study were actively seeking the views of residents in addition to using biographies and care partner involvement. These findings are inconsistent with reports that many care settings rely upon family members to make care decisions for people living with dementia, regardless of individual’s current preferences (Miller et al., 2014) and that care staff frequently make decisions on behalf of people living with dementia (Boyle, 2008). This was enabled by the positive culture observed in the care homes that was reinforced by the managers and staff and the peer support of good practice observed in the AI focus groups.

This research suggests that the principles of the MCA are applicable to everyday decisions and that biographies should only be used to support everyday decision-making where the individual is genuinely incapacitated for a specific decision at a given time. The MCA requires that *“a person’s capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it* *needs to be made"* (Department for Constitutional Affairs, 2007: p40). However, it has been recognised that *"…[the required capacity is] commensurate with the gravity of the decision"* (E.R., 1992). Whilst everyday decisions hold considerable significance for the individual, they would not be considered to have the same consequences as a major long-term decision and so the requirement to understand, remember, weigh up and communicate a decision is reduced. In addition, everyday decisions often included a greater degree of flexibility. The care staff recognised the importance of subtle fluctuations in capacity and tried to maximise the residents' involvement in decision-making by using strategies such as postponing decisions until a time the resident appeared to be more able to engage in the process.

The Impact of Communal Living on Shared Everyday Decision-Making

Despite shared decision-making being an essential element of person-centred care, embedding it in the care home context has distinct challenges. For example; care staff are often relied on to identify which decisions a resident might want (or not want) to be involved in and to what extent, there is a lack of direction in managing the process of capacity assessments for everyday low-risk decisions.

It became clear that despite offering exceptional services, choices in both care homes were limited for residents, and that impacted on how shared decision-making was enacted. The systematic review (Daly et al., 2018) identified a lack of available choices as reducing opportunities for shared decision-making in care homes (Kjellberg, 2002, Smebye et al., 2012). The findings of this AI confirmed these results and the desire of the care staff to increase the choices available suggests that they recognised that. One of the recurrent negative conversations that emerged in interviews and focus groups throughout the AI process was the fact that often the least able residents had the most limited choices – for example, a lack of choice of pureed diet.

There was a strong sense of community in each unit evidenced by how people worked together and the shared values in each home. Creating a sense of community has been recommended as a basis to maximise person-centred communal care; enhancing comfort and dignity for everyone, supporting courtesy, concern, and safety, providing opportunities for choice, and offering opportunities for meaningful engagement (Calkins and Brush, 2016, Calkins, 2018). These recommendations also reflect Nolan and colleagues' (2006, 2004) six 'senses' framework: security, belonging, continuity, purpose, achievement and significance, and demonstrate the inseparable nature of the core ideals of shared decision-making, person-centred care and relationships in extended care settings (Calkins and Brush, 2016, Edvardsson et al., 2008, Munthe et al., 2012). This was especially evident during organised activities when residents and their staff and family care partners from across the home spent time together.

Both care homes had organised 'activity' or 'leisure and wellness' programmes designed to contribute to people's physical and social health (Huber et al., 2011, Vernooij-Dassen and Jeon, 2016, Vernooij-Dassen et al., 2010). A psychosocially 'enriched environment' is central to Nolan and colleagues (2006, 2004) vision of relationship centred care where staff are valued, and family care partners feel involved. Staff in this study were not only approachable and seemingly careful to promote comfort, dignity and safety for all the residents and care partners, they openly expressed genuine fondness and even love throughout observations, interviews and focus groups. Equally residents and care partners conveyed great affection for some care staff.

The care staff in both care homes appeared to recognise how social and physical restrictions influenced the choices available to residents and where possible adjusted routines to maximise residents' comfort and minimise distress in terms of privacy and freedom of movement. Dewar and Nolan (2013) advocate the need to work together to create a solution focused culture that enables people to be open and honest while acknowledging the impact of organisational constraints. In the same way that environmental aspects of communal living limited resident choices, they also limited opportunities for staff to use enabling factors to facilitate shared decision-making, for example lack of time to take residents out more.

Care home staff demonstrated great skill in managing residents' multiple needs and wishes within organisational and environmental boundaries. However, this skill was not always apparent to the staff themselves and neither the residents or their staff and family care partners appeared to recognise the impact of these adjustments on everyday decision-making. The delivery of essential care (such as personal care or feeding residents) was often shaped by who else was present, conflicting care needs of other residents and overriding procedures. As such, everyday decision-making was often influenced and shared by more than two people.

Hughes and Baldwin (2006) have recognised that it may not be possible to meet every individual's needs in an acceptable timeframe in a communal environment. However, in this study understanding individuals' preferences and choices enabled the staff to make minor adaptations to their routines (for example, in the order that they dispensed medication) that resulted in them meeting more individual needs. My results also reflect those of Heid et al. (2016) who noted that in instances where this type of small adjustment was impossible, staff used their creativity to establish a compromise between multiple resident's needs and wishes and maintaining organisational culture and requirements.

Enablers of shared everyday decision-making

The enabling factors of shared everyday decision-making were identified as: Communication, choice, decision partner, time, environment and encouragement. These factors were most successful when they were used to impart additional information about available choices; for example, using visual aids such as juice cartons when offering choices at breakfast. Enabling factors were used predominantly by care staff and often creatively combined to achieve a positive decisional outcome for the person living with dementia. Underpinning these six enabling factors appeared to be an element of relational understanding. This has been identified as dependent on people working together to recognise who they are, how they feel and what matters to them most (Dewar and Nolan, 2013). In turn, relational understanding is significantly dependant on effective communication (Clarke and Davey, 2004, Godwin, 2014, Milte et al., 2015, Murphy and Oliver, 2013).

Relational Communication

Effective communication with people living with dementia is thought to rely on staff not only knowing residents well, but also having positive relationships with them (Eggers et al., 2013, Stanyon et al., 2016, Ward et al., 2008). 'Caring Conversations' (Dewar 2011, Dewar & Nolan 2013) is a useful framework that facilitates skilled human interaction and compassionate care as essential prerequisites of positive care relationships. It focuses on seven points; courage, emotional connection, curiosity, celebration, collaboration, compromise and consideration of others' perspectives. Collaboration and consideration of others' perspectives were apparent in all the relationships between the residents and care staff in this study. However, the other elements were not always present in what were perceived to be positive interactions. This may have been due to the specific focus of this study on shared decision-making or possibly reflect on how the quality of interactions may be measured from different perspectives.

The systematic review (Daly et al., 2018) highlighted that staff and family care partners frequently underestimated the desire and ability of people living with cognitive impairments to express preferences about their everyday life and care (Horton-Deutsch et al., 2007, Kjellberg, 2002, Samsi and Manthorpe, 2013, Smebye et al., 2012, Tyrrell et al., 2006), even in positive long-term relationships. When combined with the lack of cohesion between care partners and people living with dementia in the decision-making process (Hirschman et al., 2005, Tyrrell et al., 2006, Whitlatch et al., 2005), it raises questions about the role of consultees under the Mental Capacity Act (Department of Constitutional Affairs, 2005). However, as it appears that the process of sharing in decision-making is as important as the decision itself for people living with dementia (Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Godwin, 2014, Horton-Deutsch et al., 2007, Tyrrell et al., 2006), the individual's perception of successful shared decision-making may be more important than their level of involvement, or even the decisional outcome.

People living at home with dementia are thought to have an emotional 'transference' with their spousal care partners (Hodgson and Craemer, 2013) - meaning that they are likely to be affected by each other's emotional state. This type of relational communication develops between care partners over time and results in a values based system, grounded in trust, that facilitates shared decision-making and prioritises outcomes for both partners (Sinclair et al., 2018). The importance of interdependent relationships between family care partners and a person living with dementia, for shared decision-making, is well established in the home environment (Boyle, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Menne, 2008, Samsi and Manthorpe, 2013). However, little is known about whether care partner type relationships are reflected between people living with dementia and the staff in care homes. What is clear is that a level of mutuality is argued to be essential for a decision to be truly shared (Bekker, 2009) and relationships between people living with dementia in extended care and their care staff become increasingly significant as dementia progresses. As care needs increase and communication capabilities dwindle, care staff who know and understand the residents are better able to care for them.

I observed and was told about relationships between some care staff and ‘their’ residents that that suggested a ‘care partner’ type relationship might exist; however, it was difficult t

o identify what specifically enabled this relational understanding as this was not a focus of my study. Cameron and colleagues’ (2018) have similarly suggested that residential care staff and people living with dementia could develop family type relationships based largely on the amount of time they typically spend together. Small and colleagues (2015) observed ‘responsiveness and respect’ in positive connections between residents and their staff and family care partners and Clarke and Davey (2004) and O'connor and Rigby (1996) recognised a warm interpersonal style. ‘Warmth’ is a difficult trait to quantify or explain. In this study, the term is attributed to staff that were considered to be; friendly, cheerful, funny and/or playful, and built a greater rapport with people regardless of their dementia trajectory or communication ability.

Care staff that built strong interpersonal relationships with people with more advanced dementia often adapted their communication style to involve that individual in their everyday decisions. However, when *resident participants* discussed shared decision-making, they spoke about selecting a decision partner based on the decision to be made, not on their relationship with the decision partner. For example, they might go to the person in the office rather than a member of staff or a family care partner. This finding offers a counter narrative to previous research which accepts the centrality of the link between shared everyday decision-making and relationships (see for example, Boyle, 2014, Cameron et al., 2018, Clarke and Davey, 2004, Fetherstonhaugh et al., 2013, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Menne, 2008, Samsi and Manthorpe, 2013). The potential reasons for conflicting results include the limited understanding about communication and shared everyday decision-making from the perspective of people living with dementia. However, this finding could also be related to the finding that relationships and emotional connections alone were not sufficient to guarantee shared decisions without the presence of at least one enabling factor in this study.

Staff and family care partners believe that effective communication enhances relationships and as a result, shared everyday decision-making with people living with dementia. It therefore follows that communication difficulties have the potential to have the opposite effect, resulting in a negative impact on person centred care and ongoing personhood (Edvardsson et al., 2010, Kitwood, 1997b).

Tools such as Talking-Mats (Murphy *et al.*, 2005) have been developed to support communication and are reported to have positive outcomes in a range of settings (Bailey et al., 2011, Ferm et al., 2010, Murphy and Oliver, 2013, Span, 2016). However, most existing tools rely on the staff or family care partner to determine the focus of the decision to be made, thereby disempowering the person living with dementia who the decision is about. Implementing shared decision-making tools in care homes could place additional time and resource constraints on the care staff and their organisations as staff develop the skills required to use such aids.

The care homes in my study did not use any formal tools to facilitate communication between staff and residents. Staff did, however, demonstrate an awareness of the importance of non-verbal communication in engaging with residents and assessing whether they wanted to be involved in specific everyday decisions. Understanding and involving residents who have lost the ability to verbalise their wishes adequately, relies on staff and family care partners recognising and reacting to subtle differences in resident's communication habits (Cameron et al., 2018, Eggers et al., 2013, Savundranayagam et al., 2007). This suggests that relational factors may be more important than tools to support shared decision-making and the wider communication experience (Alsawy et al., 2017, Day et al., 2011, Savundranayagam et al., 2007).

Participants living with dementia highlighted that they understood sensory impairments (including deteriorating sight) as communication difficulties that compound challenges arising from dementia. My findings correspond with previous research suggesting that care staff can employ targeted communication strategies if they know the person well and can differentiate between sensory and cognitive impairments, and contributing environmental factors, such as background noise

(Pryce and Gooberman-Hill, 2011, Slaughter et al., 2014). Staff and family care partners in both homes tailored strategies to meet individuals' sensory and communication needs, although when asked about communication difficulties most identified verbal and behavioural difficulties rather than sensory impairments. A recent review of multi-sensory interventions for people with advanced dementia in care homes found minimal evidence about how sensory impairment affected people's ability to engage (Bunn et al., 2018b). It is important that we consider how we can ensure that we include sensory impairments when we are assessing an individual ability to participate in the shared decision-making process.

A range of practical communication strategies were used by staff and family care partners aid shared everyday decision-making. Although the strategies used reflect some of those recommended by health and support organisations (for example, Alzheimer's Society 2016), my findings echo those of Small and Gutman (2002) who found that staff and family care partners prioritise communication strategies that worked best for them. Avoidance of interruption and provision of time to talk are considered particularly useful for home dwelling people living with dementia (Small and Gutman, 2002). However, avoiding interruption and ensuring adequate time to talk were presented as challenging for care staff in the care homes and during the AI process they 'dreamed' of having more time to talk to the residents.

Time and Environment

Despite competing demands on their time, care staff regularly made time to enable residents to share, and to change their minds about, their everyday decisions. This contrasts with results from the systematic review where community dwelling people living with dementia expressed disappointment about not being given enough time to reflect on decisions or the opportunity to change their minds (Tyrrell et al., 2006). Care staff appreciated that residents changing their mind was not about inconsistency of choices, which has been explored in some depth in dementia care (Feinberg and Whitlatch, 2002, Menne and Whitlatch, 2007, Menne, 2008, Whitlatch et al., 2005). It was more about the care staff creating reflective space for them and demonstrating how attuned they were to residents' changing needs and wishes. Staff and family care partners used the reflective space to; share decisions when people were most able (Department for Constitutional Affairs, 2005), make in-the-moment decisions (Thaler and Sunstein, 2008), and to consider additional information associated with choices, making decisions more robust.

Encouragement and the Balance of Power

Shared-decision-making is considered to represent a degree of equality, even in the context of dementia care (Smebye et al., 2012). In this study, encouragement enabled people living with dementia to participate in their everyday decision-making, but it did not necessarily promote equity in the decision-making process. Involvement was often (but not always) weighted towards the staff or family care partner leading or supporting the decision-making process. An example of this is presented in Table 18, where a member of staff coaxed a resident to eat in a communal area and socialise with her peers. She recounted multiple positive outcomes for the resident, in that; she ‘ate well’, met new people, and ‘had such a lovely conversation’. Staff and family care partners often used encouragement to promote shared decisions that they perceived to be ‘good’ or ‘healthy’ (such as getting out of bed, walking, socialising or taking medication). Little is understood about the degree to which acquiescence with encouragement plays a part in shared decision-making in care homes and this is a potential area for further study.

Decisions were often made together by residents and their staff and family care partners through negotiation and compromise over extended periods of time (for example, care staff giving residents time to think about how they would like their personal care provided). However, some seemingly autonomous or independent decisions were being facilitated or influenced by the creativity and flexibility of the staff and family care partners (for example how, when and where people would have their breakfast on a high needs dementia care unit). This chimes with the findings of Fetherstonhaugh et al. (2013), whose participants living with dementia identified the importance of subtle support in the decision-making process. Subtle environmental adaptations were regularly used by care staff, in this study to position the person as capable of reciprocating communication and influencing the decision, which are as important for shared decision-making as offering support throughout the process (Boyle, 2014, Downs and Bowers, 2014, Smebye et al., 2012, Tyrrell et al., 2006).

Care staff are expected to tailor care to meet the needs and wishes of the person living with dementia and their care partner (Brooker, 2004, Edvardsson et al., 2017, Edvardsson, 2008, Kitwood, 1997a). For some staff the responsibility of weighing the resident's human rights against their duty of care to 'protect' residents could be challenging and even distressing. Care staff found it difficult if they saw a care need that they believed should be met but it was against the person's wishes; this delicate balance has been recognised in a range of care settings (Fourie, 2017, Koch et al., 2006). It is further complicated in dementia care by residents' potentially fluctuating mental capacity. This is a complex area that is enshrined in law see for example, Oldham MBC v GW and PW [2007] EWHC 136 (Fam). The 'protection imperative' could be perceived as contradictory to person-centeredness as an ethical approach in understanding people as independent individuals (Edvardsson et al., 2017).

The AI Process

The AI study participants co-created interventions that they believed would have a positive impact on how they shared everyday decisions in their care homes. All participant groups were involved throughout the AI, and the process was modified for many of the resident participants to suit their needs and wishes. As the facilitator I applied a generative perspective of AI, accepting that participants' new ideas, theories and models are the most important aspect of the process, creating new opportunities, decisions and actions (Bushe, 2010, Bushe, 2011, Bushe and Kassam, 2005). This differs from some other AI studies that have provided long-term care environments with best practice standards or available evidence to support them to make developments in a more prescribed way (see for example, Amador et al., 2014, Yoon et al., 2011).

The importance of involving the right people in the AI process is well established and Clouder and King (2015) claim that engaging a 'core group' of the 'right' participants may be as successful as engaging the whole organisation. Identifying these individuals and what makes them the 'right' people is not described in the literature, although there is some evidence that curiosity, open mindedness, communication skills and insight may be important characteristics (Bushe, 2011, Bushe and Kassam, 2005, Grant and Humphries, 2006). Care staff participants in this study predominantly self-identified. Participants who took responsibility in progressing ideas through the stages of the 4D cycle tended to be care staff who were communicative, confident, enthusiastic and inclusive in focus groups and interviews. They were offered the opportunity to volunteer and/or nominate people to take ideas forward and they welcomed the opportunity to contribute in this way. It generated lots of laughter, but also a sense of ownership, recognition and feeling valued by their peers. This process of valuing the contribution of care staff is particularly important in care homes (see for example, Godwin, 2014, Meyer et al., 2006, Nolan et al., 2006).

People living with dementia and communication difficulties were able to engage in an AI process that was adapted to meet their individual needs. They were observed to enjoy sharing their stories, and some wanted to make specific contributions to developments in the care homes (for example, the residents input in management of the home). Significant innovations may arise from unheard voices in organisations (Bushe, 2011, Cooperrider and Whitney, 2001, Whitney and Trosten-Bloom, 2010). It has been suggested that consulting residents living with dementia in care homes has a positive impact on their quality of life and self-esteem (Godwin, 2014), although Froggatt and colleagues (2009) have warned that residents must be made aware that not all ideas would be implemented.

Care staff said that they valued the time and space to create and develop ideas and to work together as a team and appreciated their ideas being considered. The *My* Home Life movement encourages staff participation, empowerment and equality to support practitioners, promote job satisfaction and increase the quality of life in care homes (Meyer et al., 2006, Meyer and Owen, 2008, Owen and Meyer, 2012). However, the positive nature of AI was challenging for some of the staff and family care partners and occasionally they reverted to problem solving or telling stories about difficulties. I promoted reflection throughout the AI process to enable staff and family care partners to talk about what was difficult for them and recognise how those difficulties might be multidimensional and feel different depending on the perspective of the individual (Bushe, 2011, Oliver, 2005a, Oliver, 2005b). The resident participants remained positive throughout the process and only one resident participant made any negative comments. Research suggests that an appreciative lens can be used to address participants real concerns by exposing negative experiences, which can lead to changes in practice and positive outcomes for the individual and the organisation (Bushe, 2010, Bushe, 2011).

Transferability is not an aspect of AI that is widely discussed – even in methodological critique (Bushe, 2011, Clouder and King, 2015). This may be due to the centrality of the participants in the design and implementation process, meaning that each AI is context driven and outcomes are specific; implementing distinctive ideas with each reaching unique destinies.

However, results of the ‘Discover’ stage of this study are considered to be transferrable to comparable participant groups in similar care home environments. For example, stories and observations of shared decision-making between people living with dementia and their staff and family care partners are representative interactions of people living with varying types and stages of dementia and the people that care for them in care homes. The factors that enable the interactions are equally transferrable in context.

How Ideas Progressed Through the 4D Cycle

Dream ideas were discussed and progressed or abandoned by participants. Most of the initiatives that were progressed from dreams to the design stage of the 4D cycle were intended to enhance communication and opportunities for extending choices related to activities. The ‘post office/shop’ and ‘one to one care staff’ were highlighted by participants as creating opportunities for staff to take time to be with individual residents.

Cooperrider’s original (1987) method for AI called for a ‘collective discovery process’. The collective discovery meant that some ideas were relevant in ways that were not immediately apparent. For example, abolition of uniforms represented equality in shared decisions and extended activities and 1:1 care staff ideas were integrated to create an outcome that was initially perceived to be unachievable (1:1 activities).

During the design stage, ideas motivated by observations and narratives of what was important to some residents were more successful if they included the residents ‘voices’ or perspectives. This was evident when a lack of interest from residents stalled the idea of the ‘man cave’. Similarly Oliver (2005a) noted that most successful interventions were influenced by people with honest and authentic input. Ideas recognised as having a potential detrimental effect on some participants they were less likely to be pursued: For example, the uniform was identified as making it harder to recognise care staff, and some participants felt that simplified or picture menus may reduce residents’ self-esteem, although they have been successfully implemented elsewhere (Clarke, 2009). In addition, changing uniforms or menus would have required organisational change and the participants were more likely to choose changes they could achieve themselves.

Ideas that were progressed through to the destiny stage of the 4D cycle included the information board and the post box and less visible ideas including 1:1 time with activity staff and plating multiple food options. There is a danger that more tangible outcomes of AI could become symbolic of a successful intervention. For example, the post box is a prominent reminder of the AI taking place in one of the care homes. Such symbols can provide an interpretation and visual representation of successful culture change in an organisation (Cameron, 2008, Detert et al., 2000, Scott et al., 2018). However, symbolism does not appear to be discussed in the AI literature other than in the dream stage of the 4D cycle, which “often results in something more symbolic, like a graphical representation” (Bushe, 2011 p. 3). The imperative to ‘do something’ could risk losing more nuanced changes in behaviour and care approach that were discussed but were not as apparent to visitors and other care staff in the homes.

A popular dream idea was to have 1:1 care staff available for everyone living with dementia and communication difficulties. This was not considered practical, but one care home initiated 1:1 activities for residents living with dementia. The evidence for individualised activities for people living with dementia is inconclusive, largely due to a lack of consistency in definitions, types of ‘activity’ programmes and measures (Edvardsson et al., 2014a, Möhler et al., 2018). Anecdotal evidence from this study suggested a positive impact on resident outcomes, although the intervention was in its infancy at the end of the study. Moments of connection, created through one to one non-task based activities, are important to people living with dementia (Bunn et al., 2018b).

Another initiative generated a gradual change in practice. It resulted from a member of staff sharing a simple story about plating both food choices for a resident living with dementia; stimulating his senses to enable him to make a more informed decision about what to eat. Ortega et al. (2012) has suggested that physically offering choices in this way can support people living with dementia in care homes to make a decision. The power of the AI 4D cycle meant that this story (and as a result, the practice) of plating multiple food options for residents spread across the units and the care homes.

Organisational Culture

The underlying values, assumptions and expectations, that characterise the culture of an organisation and its members (Cameron, 2008, Scott et al., 2018) affect the way that its members think, feel, and behave. Cameron (2008) suggests that most people are unaware of their culture and its defining attributes, until it is challenged or made explicit to them. This study intended to highlight positive aspects of organisational culture and practice related to shared everyday decision-making to participants. The approach was intended to promote the success and sustainability of any interventions by engaging organisational members in the practice development (Bushe, 2011, Bushe and Kassam, 2005, Cameron, 2008).

AI studies are often designed to have a transformational effect on organisational culture (Trajkovski et al., 2013, Watkins et al., 2016). However, in this study, participants demonstrated a slightly different approach to the 4D cycle, where they modified the ideas to *fit* the organisational culture, rather than targeting the culture itself. Although this maps with the improvisation model, where multiple ideas are developed and progressed (Bushe and Kassam, 2005, Dewar and Macbride, 2017), it may be because participants felt that existing organisational processes and cultures were positive and did not require alteration. Alternatively, they may have made unsuccessful attempts to change the culture before. My sense was that the former was more likely because prior to the commencement of this study there appeared to be a high level of democracy in both care homes and the assessment of the care homes' readiness to engage had proven positive.

Assessing the readiness of the care homes to participate in the research ensured that the overarching focus on shared everyday decision-making aligned with the beliefs, values and priorities of the residents and their staff and family care partners as well as the care homes' leadership teams. A positive care home culture (including investment in time and resources to improve staff support and ownership of organisational development) is thought to have an impact on the uptake of innovations or interventions (Goodman et al., 2017). The AI methodology recognised and reinforced current good practice and offered ongoing consultation opportunities for participants – also factors proposed as important in change implementation in care homes (Goodman et al., 2017).

Role as practitioner and researcher

The interface between my role as an experienced Registered Nurse (RN) and District Nurse (DN) and my role as a novice researcher raised some interesting and challenging issues for me. I believed that my training as a Best Interest Assessor (BIA) and experience of working with people living with dementia and their staff and family care partners in a variety of community settings, would prepare me for undertaking this study. However, I was still unable to anticipate all the ethical and practical scenarios that I encountered in my fieldwork. My professional background and belief systems inevitably had an effect on my interpretation of events in fieldwork and data analysis. This was countered through supervision and reflection on different explanations for what was being observed. It was apparent though, that my professional status promoted my credibility with the care home staff and managers and had an impact on the way that I encountered everyday care. For example, assigning meaning to a participant story or making a clinical judgment. However, all social research is inherently biased by the positioning of the researcher (Bushe, 2011, Conneeley, 2002, Cooperrider et al., 1995, Reed and Procter, 1995). I remain bound by the NMC Code of Conduct (2015) and accessed regular clinical and academic supervision throughout 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:

- Participants knew that I was not assuming a clinical role and I was careful not to offer clinical opinions on care.
- I maintained detailed reflective diaries that included changes and developments and an account of how my own values and perceptions may have influenced the research process throughout my fieldwork to promote ethical transparency (Luff et al., 2015).

My belief system includes a person-centred confidence that people are capable of influencing their own outcomes (Rogers, 1957). The research questions and the resulting design and methodology reflect my desire to focus on the extant abilities of each person living with the effects of dementia. I recognise that I have a strong bias for hearing the voice of people living with dementia and that co-created communities (such as care homes) are influenced by the preferences and choices of those constructing them (Gergen, 2009). As such, I considered the use of process consent (Dewing, 2007, Dewing, 2008) an ethical imperative, progressing inclusion, empowerment and choice for people living with dementia to shape their ongoing experiences (see for example, Bartlett and O'connor, 2010, Dementia Action Alliance, 2019, Hubbard et al., 2003, Martin and Younger, 2000a, Martin and Younger, 2000b). However, process consent carries a huge personal and professional responsibility. As a BIA I have a strong working knowledge of the Mental Capacity Act (2005) but ensuring that residents living with dementia were willing and able to participate in my study required objective self-awareness as well as knowledge and skill. Navigating and applying the core principles of the MCA and ethical protocols required me to repeatedly use my clinical judgement. At times, particularly on high needs dementia care units, this had an emotional impact on me (Lee-Treweek, 2000).

Data Collection

Prior to interviews and focus groups I completed 18 hours of observations in each care home. Not actively participating in care was difficult, especially when residents were calling for support and the care staff were with other residents. There were occasions where I did intervene in small acts of care (for example, helping a resident with a drink or holding their hand). These incidents were rare, but not ’caring’ was the hardest part of fieldwork for me. More common were episodes when residents were wanting to engage me in conversation either about what I was doing or what they used to do. Residents often invited me to sit with them for meals and drinks, or even chose to sit next to me in a lounge area and hold or stroke my hand. I found all these episodes extremely heart-warming and was happy to be included by them in their everyday lives.

The definition of, or allocating ‘levels’ to, shared everyday decisions was an unexpected challenge during data collection. Some decisions that appeared autonomous were actually facilitated by care staff (and therefore potentially shared in some way). The reflective extract below is from my first observation in Treetops.

> …someone went from [unit] independently, in their wheelchair, out into the main coffee area. They appeared to have complete control over the decision to go out of the unit and into the coffee area, but that decision must have been facilitated in some way because [unit] is sometimes locked…

I found interviews and focus groups easier to manage than observation. I used the ethically approved interview schedule as a framework (Appendix 3) and rarely strayed from the prescribed questions and prompts. On reflection, this may have been because I viewed the ethics approval as a safeguard to protect the research participants. I drew on my experience as a counsellor, coach and health professional rather than developing or 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., 2014b, Webster and Dewing, 2007) and my interview style was positive, chatty and friendly. The repetitive nature of the 4D cycle meant that I had the opportunity to develop a rapport with most participants over a period of time, which helped me to engage with them and enabled them to ‘open up’ to me (King and Horrocks, 2010, Kvale, 2008). AI also meant that collecting and validating positive participant stories and dream ideas, promoted a relationship that evolved throughout the process. Social, emotional and moral relationships between the facilitator and participants (Dewar and Macbride, 2017, Luff et al., 2011) are thought to enhance successful change in care home environments (Ashburner et al., 2004, Brown-Wilson, 2009). The impact of these relationships is demonstrated in the following diary extract:

> The staff are … really ground down. It is hard for me to see them so flat, bearing in mind how happy and upbeat they normally are… This has been a tough couple of days ... I feel really emotionally exhausted in a way that I haven’t really experienced since I did my first couple of days of observations. I am coming back on Tuesday next week to do another focus group with 4 more care staff and I am hoping that, that might be a little bit more positive, but I need to prepare myself for the fact that it might be very similar.

Communication difficulties and the effects of dementia may have made involvement in interviews and focus groups challenging for resident participants. I made every effort to manage Interviews and focus groups sensitively, and timeframes and language were led by the participant as suggested by Cameron et al. (2018), Mckillop and Wilkinson (2004). No participants acknowledged any problems with the process. They accepted this as an appropriate way of promoting understanding of what they considered to be ‘good’ communication and how they can be more effectively involved in research and shared everyday decision-making (Alsawy et al., 2017, Department of Health, 2012a). However, there were individuals who I was unable to effectively communicate with; either due to confusion, loss of language or a combination of factors. I felt a sense of failure each time that I was unable to interview the one gentleman who I could not connect with enough to include. He always smiled and reached out for my hand when I saw him, but when his wife (his consultee) was present, he was sleeping, and I interviewed her alone. Other participants with consultees were present in the interviews but I am unsure how much of their personal thoughts or feelings I was able to capture.

Interviews were ended in a relaxed manner (Bowling, 2014) and I asked participants if they had anything that they wanted to ask or add. Some resident participants used this as an opportunity to continue the conversation and I often stayed and chatted with them after their interviews or focus groups (Hubbard et al., 2003, Mckillop and Wilkinson, 2004).

Contribution to knowledge

This is one of the first studies to evaluate the involvement of people living with dementia in everyday decision-making in care homes. It offers new understanding, insights and evidence of the decisions that people living with dementia make and share in care homes and who they share them with.

Through the systematic review, staff and family care partners were found to underestimate the importance of continued participation in decision-making for people living with dementia. A lack knowledge was identified in how shared everyday decision-making is enacted with people living with dementia in a communal environment where choices are limited.

This study demonstrates how, despite organisational, environmental and organic factors, people living with dementia can be supported and enabled to participate in the everyday decisions about their life and care. Staff and family care partners used person-centred care informed by residents’ current preferences and documented biography. The study also provided new insights into how staff and family care partners in care homes use their experiential knowledge and a willingness to try new approaches to explore decision-making opportunities through increased choices, awareness and information exchange.

Six factors that consistently enabled and facilitated shared-everyday decision-making in the care homes were identified; encouragement, communication, choice, environment, decision partner and time. These factors did not require participants to access any additional training or tools, as they were already demonstrating their use across a variety of decisions. Their use does, however, need to be recognised and encouraged.

A new definition of shared everyday decision-making for people living with dementia in care homes is proposed. The definition recognises that what shapes decision-making interactions can be as significant as the decision itself and the importance of the ‘voice’ of the person living with dementia. It also demonstrates the potential and power of creating communicative space for residents and their staff and family care partners to utilise appropriate levels of relevant information (or ‘evidence’) in a way that it accessible and mutually beneficial.

The data here adds to the limited body of evidence examining what constitutes good communication from the perspective of people living with dementia (Alsawy et al., 2017, Cameron et al., 2018, Machiels et al., 2017). Participants stories about shared everyday decision-making add awareness of the impact that sensory impairments have on communication difficulties for people living with dementia and serve to recognise and highlight existing good practice in care homes – with staff routinely using sensory stimulation to support the decision-making involvement of people living with dementia in their everyday care.

Appreciative Inquiry is widely accepted as a useful methodology in care home research (Amador et al., 2016, Meyer et al., 2006, Yoon et al., 2011). However, few studies have included participants living with dementia and communication difficulties in care homes in the process (Cameron et al., 2018, Machiels et al., 2017). In engaging people living with dementia alongside their staff and family care partners, this study positions all participants as equal and ensures that the stories and perspectives people living with dementia are not only documented, validated and disseminated, but that they are used to achieve the participants desired outcomes.

Strengths and limitations

Using AI allowed me to access the stories and insights of people living with dementia and communication difficulties as well as their staff and family care partners. Each participant and their stories and ideas were equally valued, which aligns with recommendations that all residents, staff and family care partners have equal worth (Luff et al., 2011). This approach meant that participants felt appreciated, remained engaged throughout the entirety of the study and co-created all the innovations. The AI 4D cycle was completed with five innovations implemented by the participants. AI proved to be an acceptable methodology for people living with dementia and their staff and family care partners to develop shared everyday decision-making with minimal ‘light-touch’ external facilitation. Observational data corroborated narrative accounts of shared everyday decision-making, which was also considered a considerable strength of the study.

There were limitations associated with using AI as a methodology for people living with dementia; for example, their difficulty engaging with the abstract nature of the dream stage of the 4D cycle. A more directive style of facilitation which offered participants examples of best available evidence or focused on a particular everyday decision-making field may have produced different results and may have been easier for people living with dementia to engage with. Where interviews and focus groups were combined for people living with dementia and their family care partners to incorporate the whole 4D cycle, it was not possible for them to fully embrace and complete the process. This was largely because there was not an opportunity for reflection between stages or time for implementation of change in practice. Whilst this is acknowledged as a limitation, Clouder and King (2015) echo the point made by Reed (2006) that transparently reporting how the AI process was adapted and implemented will promote the comparability and replicability of future AI studies in health and social care (Trajkovski et al., 2013). In addition, this approach provides empirical evidence about how AI can work with people living with more advanced (mid trajectory) dementia.

The long-term impact of the AI process has not been measured or monitored and this is a limitation although it is a widely recognised limitation across AI in healthcare studies (Watkins et al., 2016) and more generally (Clouder and King, 2015, Grant and Humphries, 2006, Van Der Haar and Hosking, 2004). The limited long-term evaluation of this study was largely due to the study time frames. However, I have maintained ongoing critical reflection throughout the study as a form of evaluation in line with recommendations (Clouder and King, 2015, Luff et al., 2015, Van Der Haar and Hosking, 2004) and this this is considered to partially mitigate the limitation.

Other limitations of the study included my lack of specificity in defining shared everyday decision-making for participants. This was because I wanted to understand how they understood and conceptualised it. A clearer definition of shared decision-making may have made the process easier for participants and facilitated more focused innovations. Alternatively, it may have constrained creativity and the development of ideas.

The tools selected as measures for quality of life and communication difficulties could not be used as I had initially planned. This may be because I attempted to use them for a purpose for which they were not developed. However, the DCDS score provided information on individual’s areas of relative strength and difficulty, providing a communication profile to promote and inform effective communication in interviews and focus groups. Not assigning resident participants with a medicalised measure of their dementia may be considered a limitation, as systematic reviews typically group participants living with dementia under their MMSE (Folstein et al., 1975) or similar score. However, no scoring system would have been able to capture the fluctuating nature of how some individuals’ dementia affected their ability to participate in decisions about their everyday life and care.

Homes where the manager had attended the *My* Home Life leadership support programme were specifically targeted, and this may have had a significant impact on the homes’ familiarity with and ability to support this type of participative AI study. The transferability of this research may be considered limited by working with exceptional care homes and the unusually high levels of participant engagement. However, these care homes were not exceptional in the resources available to them and the resident populations that they care for.

The results of the ‘Discover’ stage of this study are considered to be transferrable to comparable participant groups in similar care home environments. For example, stories and observations of shared decision-making between people living with dementia and their staff and family care partners are representative interactions of people living with varying types and stages of dementia and the people that care for them in care homes. The factors that enable the interactions are equally transferrable in the appropriate context.

This study was practice driven and undertaken by an experienced nurse who has a genuine passion for supporting care home staff to embed shared everyday decision-making with people living with dementia into everyday practice. My enthusiasm and passion combined with appropriate skills and experience may have had a positive impact on the level of engagement in the study.

Implications for research

Areas for future research identified by the study include:

- Building on the understanding of how choice and encouragement are offered to maximise the ability of an individual living with dementia and communication difficulties to participate in decision-making.
- Exploring how sensory stimulation can help people living with dementia and communication difficulties to engage in shared decision-making.
- Understanding the nature of shared decision-making in the context of communal living and the role that collective decisions play in successful shared decision-making with people living with dementia in care homes.
- How care partner type relationships between people living with dementia and care staff influence the sharing of everyday decisions in care homes.

Implications for practice

Some of the innovative ideas that emerged from this study are easy to replicate in other care homes. For example, plating and physically offering residents living with dementia more than one food choice at mealtimes increased their ability to make a choice and took minimal time and effort on the part of the care staff. Care homes could explore the cost implications associated with offering all residents the opportunity to make in-the-moment decisions about their food choices due to the high numbers of residents living with dementia on nursing care units.

Care homes can creatively engage with people living with dementia and their staff and family care partners to identify innovative ways to recognise and embed shared everyday decision-making. Giving care staff the reflective space to develop ideas is a positive way for care homes to promote social capital and informal interactions that enhance job satisfaction and caring capabilities (Aloisio et al., 2019, Cheng et al., 2019, Kishita et al., 2018).

Multiple senses were seen to have an impact on residents' ability to participate in decision-making and this simple practice can be replicated and promoted to reduce staff and family care partner reliance on biographies and enable the person to participate in decisions in-the-moment. Documenting the senses that work well for an individual could enhance their extant abilities and enable them to continue their involvement in their everyday decisions into late stage dementia.

People living with dementia considered hearing and visual impairments to have a significant impact on their day-to-day ability to communicate effectively. Many care homes (including those in this study) have effective methods for ensuring that sight and hearing tests are regularly carried out for people who are able, and that visual and hearing aids are well labelled and regularly monitored. This needs to be prioritised across all care homes especially for people living with dementia who have the additional challenges of cognitive impairment and potentially resulting communication difficulties.

Care homes that prioritise shared everyday decision-making should advertise their commitment to prospective residents and their family care partners. Dementia is more feared than any other health condition (Alzheimer's Research, 2015), and this may be related to the loss of control associated with the effects of dementia. This study shows that people living with dementia and communication difficulties in care homes can retain an element of control by participating in the everyday decisions that affect their life and care. Therefore, people living with dementia and their family care partners should feel confident that care homes which embrace shared everyday decision-making are enabling residents to live well with dementia.

Regulatory authorities could prioritise the importance of shared decision-making as an essential element of person-centred care and its impact on an individual's control over their daily life and care when assessing the quality of provision. This would ensure that care settings that are maximising residents' participation in everyday decision-making would be recognised for their contribution to the promotion of empowerment, enablement and retained abilities of people living with dementia.

Conclusions

Shared everyday decision-making is a legal and ethical imperative of the Mental Capacity Act, the Convention on the Rights of Persons with Disabilities and an integral element of person-centred care. However, it is most often recognised in relation to life changing decisions about advance care plans, place of care and healthcare treatments. This study has focused on the detail of the everyday decisions that people living with dementia and communication difficulties make and share in care homes. It has demonstrated that they are both interested and able to be involved in the planning and delivery of their everyday care.

Shared decision-making maximises inclusivity in dementia care, but multiple definitions shape how it is understood and operationalised in practice. Sharing decisions with people living with dementia relied on the same key concepts as in the clinical sense; respecting an individual's values and preferences, sharing available information appropriately and recognising limitations. However, some everyday decisions were more easily shared than others and although the skills required to involve people in everyday decisions remained consistent, most staff and family care partners were more comfortable facilitating decisions that did not include risk for the person living with dementia. For example, decisions associated with unhealthy lifestyle choices such as smoking or alcohol consumption, featured less in participant stories and observations about shared decisions. Everyday decisions associated with food and drink, physical and social activities and aspects of personal care were frequently made and shared by people living with dementia, requiring staff and family care partners to demonstrate communication skills, creativity, compassion and patience that were aligned with the needs and essence of the person – and their current needs as well as those in the past. However, staff and family care partners were less confident in involving people living with dementia in decisions that challenged the organisational and environmental limitations associated with communal living.

Many people living with dementia were able to demonstrate the choice to make some everyday decisions independently and to share others with subtle but significant support. This level of independence appeared to have a positive effect on them and their care experience. However, the study found that exercising choice was not equivalent to making decisions and that even enacting simple choices required considerable assistance for some. The expectations associated with peoples' ability to engage in shared everyday decision-making was partially affected by the location of their care – on a nursing or dementia care unit - rather than on their individual capabilities. The care homes in this study are broadly representative of similar nursing homes in that they have specialist provision for between a third and a half of residents to be living with dementia. However, approximately three quarters of residents were living with the effects of dementia, meaning that specialist dementia care must be available across the entire home. Whilst this need is mitigated by strong leadership, excellent care and creativity, the parent organisations that own care homes need to recognise that opportunities that enhance shared everyday decision-making such as in-the-moment choices of meals, need to be available to all residents whose cognitive function may fluctuate.

Interpersonal relationships had complex effects on communication, with some residents and care staff developing bonds that reflected care partner type relationships that resulted in a greater recognition and understanding of the residents' desire and ability to share choices and decisions. This reflects the long-term nature of the relationships that can arise in care homes that do not tend to occur in episodic clinical encounters, even between patients and clinicians who have had a long association. Recognising the importance of relational based communication in mitigating problems associated with communication difficulties and how this expertise is shared between staff is a promising avenue for future research.

Communication difficulties, including sensory impairments, had a profound effect on peoples' ability to effectively participate in everyday decision-making. In order to effectively assess and manage the way that we communicate with people living with dementia, it is important that we broaden our concept of communication difficulties beyond language and non-verbal expressions to include and address how sensory impairments affect person-centred care and more specifically, shared decision-making. Interventions that promote the use of multiple senses to enhance shared everyday decision-making are widely used by some staff and family care partners and disseminating this practice could have a positive impact on how dementia care is delivered and experienced.

The systematic review did not identify any tools or resources that empowered people living with dementia to lead decisions about their everyday life in care homes. However, the AI study revealed six enabling factors that were commonly used by participants to enhance shared everyday decision-making; encouragement, communication, choice, environment, decision partner and time. These informal and freely available factors were creatively combined and employed by people living with dementia and their staff and family care partners with positive results and minimal resource implications. Employing the enabling factors to facilitate shared everyday decisions was dependant on the experience, expertise and creativity of all the people ‘sharing’ in the decision, along with contextual factors including; resources, organisational procedures, disease progression and other people present.

As a research approach, Appreciative Inquiry (AI) was effective in building on shared everyday decision-making practices that were not immediately apparent to the participants. Resource allocation and funding were immaterial in the development and implementation of innovations that created micro-shifts in culture related to opportunities for individuals and groups to share everyday decisions. The scale and impact of the innovations varied from an information board on one nursing care unit to a post box that all residents and care partners could use and 1:1 time with an activity co-ordinator for people who no longer wished or were able to engage in group activities. Key to the implementation of innovations were skills and behaviours that supported shared everyday decision-making such as empathy, openness to new practices, strong communication skills and inclusivity.

In bringing staff together to share stories of good practice, AI fostered group cohesion and common purpose in the 80 per cent of participants that completed the full modified 4D cycle. The AI process had as much impact in helping staff to think differently about shared decision-making as an essential aspect of person-centred care as it did in being able to achieve tangible change in shared decision-making processes. Further AI work with high level organisational management is needed to truly transform residential dementia care on a wider scale.

Initiating ideas in the dream stage of AI was difficult for people living with dementia. However, their stories - grounded in personal experience - added authenticity to the process and enhanced evidence about how different types and stages of dementia and communication difficulties affected outcomes. The light touch facilitation and tailoring of the process to meet individual participants needs maximised their opportunities for involvement and respected and valued their knowledge and experience in the process. A disadvantage of the AI process however, was that participants’ ideas about how decision-making opportunities could be created or improved was shaped by the limited choices available to residents. This was evident in innovations identified to support shared decision-making being grounded in stories about increasing residents’ opportunities for choice.

Care staff contributed to a culture that facilitated shared everyday decision-making by tailoring routines and the environment to maximise choices and care experiences for multiple residents at any given time. However, the voice of the person living with dementia was not always prominent in shared decisions – especially where encouragement was used as a facilitator. More dominant were the empathy and awareness of staff and family care partners in what they believed an individual might want or like, or what they perceived might benefit their physical or mental wellbeing. Greater understanding is needed of the ways that choice and encouragement are used with people living with dementia and the effect that living in a care home may have on the decision-making interactions.

This study is one of the first to look at shared everyday decision-making including the perspective of people living with dementia in care home settings. It has demonstrated the value of using diverse and creative methods to offer decision and choice making opportunities for people living with dementia and communication difficulties. It has also highlighted the need to value an environment that appreciates the diversity of how people engage with each other and promotes risk taking in terms of routines and environmental constraints where opportunities for individual and group benefits are apparent. Above all it has identified a need to develop a more sophisticated understanding of what shared everyday decision-making entails in long term care settings.

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Appendices

Appendix 1 - Shared decision-making for people living with dementia in extended care settings: a systematic review.

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Keywords: Cognitive Impairment, Dementia, Shared Decision-Making, Care Homes, Everyday Care, Extended Care, Day-to-Day Care, Residential Care

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ABSTRACT

Background – Shared decision-making is recognized as an important element of person-centered dementia care.

Objectives - The aim of this review was to explore how people living with dementia and cognitive impairment can be included in day-to-day decisions about their health and care in extended care settings

Design – A systematic review including primary research relating to shared decision-making, with cognitively impaired adults in (or transferrable to) extended care settings. Databases searched were: CINAHL, PubMed, the Cochrane Library, NICE Evidence, OpenGrey, Autism Data, Google Scholar, Scopus and Medicines Complete (June - October 2016 and updated 2018) for studies published in the last 20 years. PROSPERO number CRD42016035919

Results. Of the 19 included studies 15 involved people with living dementia, 7 in extended care settings. People living with cognitive impairment often have the desire and ability to participate in decision-making about their everyday care, although this is regularly underestimated by their staff and family care partners. Shared decision-making has the potential to improve quality of life for both the person living with dementia and those who support them. How resources to support shared decision-making are implemented in extended care settings, is less well understood.

Conclusions – Evidence suggests that people living with cognitive impairment value opportunities to be involved in everyday decision-making about their care. How these opportunities are created, understood, supported and sustained in extended care settings remains to be determined.

Strengths and limitations;

- The review involved a systematic and rigorous search for cross-disciplinary literature relating to shared decision-making for people living with cognitive impairment in extended care settings.

- The majority of studies were conducted in the community rather than in extended care settings.
- Terminology varies across Countries, disciplines and professions potentially impacting on the studies retrieved. Including additional search terms around ‘choice’ may have identified additional relevant papers.

Word Count – 4,571

Shared decision-making for people living with dementia in extended care settings: a systematic review.

Background

For people living with dementia shared decision-making is increasingly considered crucial in health and care practice (Edvardsson et al., 2010, Hutchison et al., 2011, Stiggelbout et al., 2012, Wolfs et al., 2012) and is an essential aspect of person centred care (Edvardsson et al., 2008);the fundamental premise of which is that the individual’s priorities, interests, abilities and character should inform decision-making (Mccormack, 2004). Shared decision-making practice is equally important in extended care. Extended care is defined as residential settings that provide onsite care. This includes supported living, care villages and extra care housing in addition to more traditional care homes with and without nursing (Care Quality Commission, 2009).

A dementia diagnosis does not automatically render someone incapable of making a decision (Bartlett and O'connor, 2010, Wilkinson, 2001) but for a decision to truly be shared, mutuality must be established (Bekker, 2009). Legislative changes in the last decade have strengthened the rights of people living with dementia to participate in decisions about their care (Smebye et al., 2012, Tyrrell et al., 2006). The United Nations Convention on the Rights of People with Disabilities (CRPD), states that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (United Nations, 2006). However, evidence on *how* care decisions are currently made within various legislative frameworks, for and with, people living with dementia, is patchy and often focuses on decisions relating to life events(Manthorpe and Samsi, 2013, Smebye et al., 2012). In England and Wales the Mental Capacity Act (2005) provides a legislative framework to protect and empower people to participate in decisions about their life and care unless there is evidence to the contrary (Department of Constitutional Affairs, 2005; 2007). Evidence suggests however, that staff in extended care often make day-to-day care decisions on behalf of people living with dementia (Boyle, 2008, Manthorpe and Samsi, 2013). There are situations where people living with dementia in extended care settings decline to participate in decision-making and prefer to relinquish control and delegate to a care partner or worker. Reasons identified include; anxiety about ability to participate and reluctance to accept decreasing abilities (reported as self-protection) (see e.g. Goodman et al., 2013, Mathie et al., 2012, Miller et al., 2014).

Two reviews have focused on shared decision-making with people living at home with dementia (Miller et al., 2014, Taghizadeh Larsson and Österholm, 2014). They offer useful insight into degrees of involvement in the decision-making process, what influences that involvement and how people participate (Miller et al., 2014, Taghizadeh Larsson and Österholm, 2014).In a review of 36 studies of people living with dementia and their carers Miller (Miller et al., 2014) identified assorted patterns of decision-making ranging from 'being free to make a choice' through 'supported autonomy' to 'being reliant upon carers'. Larsson's review of 24 studies on community decisions relating to access to care services developed three themes to capture how people living with dementia experience involvement in care decisions; *excluded, prior preferences taken into account,* and *current preferences respected* (Taghizadeh Larsson and Osterholm, 2014). These reviews usefully bring shared decision-making with people living with dementia into focus but largely excluded people living in extended care settings, who are typically frailer and further along the dementia trajectory. They highlight that decisions for people living with dementia at home invariably involved a care partner/family member. However, family members are often unavailable for many of the day-to-day decisions undertaken in extended care due to time and geographical constraints.

There is increasing recognition that day-to-day decisions are potentially more significant in everyday quality of life than the more noteworthy issues such as treatment decisions or relocation (see e.g. Mariani et al., 2016, Menne and Whitlatch, 2007, Orrell et al., 2008). Building on previous work, this paper considers the evidence on *how* day-to-day decisions are understood and negotiated between people with a cognitive impairment and their (staff and family) carers in extended care settings. The review objectives are presented in *box 1.*

Box 1 – Review Objectives

- ❖ Explore how shared decision making is understood and/or characterised for people living with dementia and their (staff and family) carers
- ❖ Explore the role of (staff and family) carers of people living with dementia in shared decision-making care dyads
- ❖ Analyse identified risks and benefits associated with shared decision making for people with cognitive impairment
- ❖ Ascertain empirical evidence for the effectiveness of available shared decision-making resources for people living with dementia
- ❖ Seek to understand the barriers and facilitators to effective shared decision making for people living with dementia and their (staff and family) carers
- ❖ Explore the extent to which shared decision making has been researched in extended care settings
- ❖ Identify implications for shared decision making in dementia care practice, policy and future research

Methods

A detailed account to the review methods are published elsewhere (Daly et al., 2016a) PROSPERO registration number CRD42016035919. The review was planned and is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2015).

Results are presented to reflect relevance to the review question and objectives rather than frequency that the topic arises in the data and must represent a pattern across more than one included study to constitute a theme (Braun and Clarke, 2006).

Study selection and inclusion criteria

Inclusion criteria are presented in *Table 1* below. A time limit of 20 years was applied to reflect the rapidly changing literature on involving people living with dementia in their care, published since the seminal works of Tom Kitwood (Kitwood, 1997b, Kitwood, 1997a, Kitwood, 1997c). The main focus of the review was on people with dementia but studies relating to adults with other types of cognitive impairment were also included because of the potential for transferable learning.

Table 1– study inclusion criteria

Table 1 - Inclusion Criteria	
Publication Language	English
Publication Dates	January 1996 - October 2016
Target Population	Adults, aged over 18 years, with any type of cognitive impairment for example (but not limited to) dementia, learning disabilities, Parkinson's and Huntington's disease
Study Setting	Community living at home or extended care settings e.g. supported living, or residential care. Studies must be considered transferable to people living with a cognitive impairment in an extended care setting (for example the person living with a cognitive impairment must be in receipt of care in addition to that provided by a family care partner and the resource should be suitable for implementation in extended care settings.
Study Types	All research designs including quantitative and qualitative research.
Primary Outcomes	Any outcome relating to involvement in care planning, satisfaction with decision (e.g. care was congruent with expressed choice), quality of life or wellbeing, and behavioural changes (e.g. reduction in distress)
Additional Outcomes	Family care partner and/or health or care professional satisfaction, and any documented adverse effects (e.g. falls, weight loss, adverse outcomes related to medication management).

The term 'care partner' has been adopted to represent a family member or friend who has a caring relationship with the person living with a cognitive impairment. The terms health and/or care professionals, staff or workers are used interchangeably to describe people who are paid to provide health or social care.

Search strategy

The search strategy drew on a range of cross discipline data sources associated with cognitive impairment and dementia care. Electronic databases searched and an example of the search query for PubMed is given in *table 2*. Search terms were adapted as appropriate for other databases.

Table 2- Electronic databases searched, and search terms used

Table 2 - Search Strategy	
Electronic databases searched	CINAHL Plus, PubMed, the Cochrane Library, NICE Evidence, OpenGrey, Autism Data, Google Scholar, Scopus and MedicinesComplete
MeSH search terms (with subheadings included)	Cognition Disorders searched (((("dementia"[MeSH Terms] OR "dementia"[All Fields]) OR ("cognitive dysfunction"[MeSH Terms] OR ("cognitive"[All Fields] AND "dysfunction"[All Fields]) OR "cognitive dysfunction"[All Fields] OR ("cognitive"[All Fields] AND "impairment"[All Fields]) OR "cognitive impairment"[All Fields])) OR ("learning disorders"[MeSH Terms] OR ("learning"[All Fields] AND "disorders"[All Fields]) OR "learning disorders"[All Fields] OR ("learning"[All Fields] AND "disability"[All Fields]) OR "learning disability"[All Fields])) OR ("learning disorders"[MeSH Terms] OR ("learning"[All Fields] AND "disorders"[All Fields]) OR "learning disorders"[All Fields] OR ("learning"[All Fields] AND "disorder"[All Fields]) OR "learning disorder"[All Fields])) OR ("autistic disorder"[MeSH Terms] OR ("autistic"[All Fields] AND "disorder"[All Fields]) OR "autistic disorder"[All Fields] OR "autism"[All Fields])) OR ("stroke"[MeSH Terms] OR "stroke"[All Fields])) OR ("brain injuries"[MeSH Terms] OR ("brain"[All Fields] AND "injuries"[All Fields]) OR "brain injuries"[All Fields] OR ("brain"[All Fields] AND "injury"[All Fields]) OR "brain injury"[All Fields])) OR ("neurocognitive disorders"[MeSH Terms] OR ("neurocognitive"[All Fields] AND "disorders"[All Fields]) OR "neurocognitive disorders"[All Fields])) OR ("alzheimer disease"[MeSH Terms] OR ("alzheimer"[All Fields] AND "disease"[All Fields]) OR "alzheimer disease"[All Fields] OR "alzheimer"[All Fields])) AND Shared Decision-making (((((((shared[All Fields] AND ("Decision (Wash D C)"[Journal] OR "decision"[All Fields])) OR ("decision-making"[MeSH Terms] OR ("decision"[All Fields] AND "making"[All Fields]) OR "decision-making"[All Fields])) OR ("community participation"[MeSH Terms] OR ("community"[All Fields] AND "participation"[All Fields]) OR "community participation"[All Fields] OR ("consumer"[All Fields] AND "participation"[All Fields]) OR "consumer participation"[All Fields])) OR ("patient participation"[MeSH Terms] OR ("patient"[All Fields] AND "participation"[All Fields]) OR "patient participation"[All Fields])) OR (("Decision (Wash D C)"[Journal] OR "decision"[All Fields]) AND support[All Fields])) OR (care[All Fields] AND dyad[All Fields])) OR ("patient education handout"[Publication Type] OR "patient education as topic"[MeSH Terms] OR "patient education"[All Fields]))) NOT (((advance[All Fields] AND ("Decision (Wash D C)"[Journal] OR "decision"[All Fields])) OR ("advance directives"[MeSH Terms] OR ("advance"[All Fields] AND "directives"[All Fields]) OR "advance directives"[All Fields] OR ("advance"[All Fields] AND "directive"[All Fields]) OR "advance directive"[All Fields])) OR (advance[All Fields] AND care[All Fields] AND plan[All Fields]))) OR ((((((("Dementia"[Mesh] OR "Neurocognitive Disorders"[Mesh]) OR "Brain Injuries"[Mesh]) OR "Stroke"[Mesh]) OR "Learning Disorders"[Mesh]) OR "Autistic Disorder"[Mesh]) AND ((((("Decision-making"[Mesh] OR "Decision Support Techniques"[Mesh]) AND "Patient Participation"[Mesh]) OR "Cooperative Behavior"[Mesh]) OR "Physician-Patient Relations"[Mesh]) OR "Patient Education as Topic"[Mesh])) NOT Advance Directives("Advance Directives"[Mesh] OR "Advance Care Planning"[Mesh]))) NOT

	Paediatrics ("child"[MeSH Terms] OR "child"[All Fields])) NOT ("Child"[Mesh] OR "Disabled Children"[Mesh])
Alternate free text search terms	(Cogniti*, Disorder*, Dementia*, Alzheimer*, Neurocogniti* Dis*, Brain Injur*, Autis*, Learning Dis*, Stroke) AND (Shared Decision-making, Deci* Mak*, Patient Participat*, Consumer Participat* , Cooperat*, Decision Support) NOT (Paed* Child*) NOT (Advance Directives, Advance* care planning, Advance* deci*)
Google Scholar	The search and screening strategy for Google Scholar was agreed by all 3 authors. Free text search terms mirrored other databases. Results were filtered by relevance. The first 20 pages of results, title and abstract, were screened (20 results per page).

Reference lists of relevant primary and review articles were manually searched to detect additional studies and citation search was performed using the ‘cited by’ option on Google Scholar, and the ‘related articles’ option in PubMed. Searches were initially undertaken in June 2016 and updated in October 2016. Lateral searches were completed in November 2016. The search was updated in January 2018.

Electronic search results were downloaded into EndNote. One author (RD) screened references and, where necessary, sought support and independent review from a second author (FB or CG).

Quality Assessment and Data Extraction

Quality assessment was undertaken using the validated QualSyst Framework (Kmet et al., 2004, Laidsaar-Powell et al., 2013, Légaré et al., 2008). The QualSyst framework provides comprehensive definitions, instructions, and a scoring system for quality scoring of both quantitative and qualitative studies represented as a percentage (with a greater percentage representing higher quality)(Kmet et al., 2004). An ethical approval question was added as this has been highlighted as an essential element of study quality (Hannes, 2011, Noyes et al., 2015). Quality assessment was carried out by one reviewer (RD), with 10 per cent checked by a second reviewer (FB/CG).

Data were extracted using a structured form that addressed the review objectives. This included information about the study design, participants and outcomes.

Analysis

Due to heterogeneity, and low numbers, of included quantitative studies, meta-analysis was not considered appropriate therefore results are reported in a narrative format.

Theoretical thematic analysis was undertaken using the research question and review objectives (see *box 1*) as a framework to map the range of data and identify recurrent themes. This method of synthesising qualitative research draws on work by Braun and Clarke (Braun and Clarke, 2006, Clarke and Braun, 2014). It offers in depth exploration of the identified themes and areas of interest, which include the roles, resources, and people essential to the shared decision-making process relevant to extended care settings.

Results

Nineteen publications are included (Bailey et al., 2011, Boyle, 2014, Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Ferm et al., 2010, Fetherstonhaugh et al., 2013, Godwin, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Kjellberg, 2002, Menne and Whitlatch, 2007, Menne, 2008, Milte et al., 2015, Murphy and Oliver, 2013, Samsi and Manthorpe, 2013, Smebye et al., 2012, Span, 2016, Tyrrell et al., 2006, Whitlatch et al., 2005) relating to 18 unique studies (including a doctoral dissertation). Four of the papers are linked as they included a baseline sample drawn from the same pool of participants (Feinberg and Whitlatch, 2002, Menne and Whitlatch, 2007, Menne, 2008, Whitlatch et al., 2005). However, the studies addressed different questions and are, therefore, included as individual papers.

An overview of the screening and selection process is demonstrated in Figure 1.

Supplementary Figure 1 - PRISMA flow chart

Study Quality

Study quality ranged from 65-100% see *table 3*. No studies were excluded as a result of the quality assessment but a high risk of bias was noted in some studies, such as a measure designed by the same people as the intervention (Ferm et al., 2010). Eight studies did not provide a clear ethics statement (Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Ferm et al., 2010, Fetherstonhaugh et al., 2013, Menne and Whitlatch, 2007, Murphy and Oliver, 2013, Tyrrell et al., 2006, Whitlatch et al., 2005), including the two studies that scored 100% on QualSyst (Menne, 2008, Whitlatch et al., 2005).

Characteristics of included studies and participants

All included studies (see *table 3*) were published between 2002 and 2016. The majority (n=14) of studies were published in the last 10 years, suggesting an increasing awareness and interest in shared decision-making for people living with a cognitive impairment that reflects the progression in national and international legislation. All five UK studies were published since the full implementation of the Mental Capacity Act (Department of Constitutional Affairs, 2005).

Most papers (n=15) focus on people living with dementia (Boyle, 2014, Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Godwin, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Menne and Whitlatch, 2007, Menne, 2008, Murphy and Oliver, 2013, Samsi and Manthorpe, 2013, Smebye et al., 2012, Span, 2016, Tyrrell et al., 2006, Whitlatch et al., 2005); twelve are in ‘care dyads’ (with a care partner) or ‘triads’ (with a care partner and a health or care worker). Two papers centre on people with a learning disability (Bailey et al., 2011, Kjellberg, 2002), one on people living with Huntington’s disease (Ferm et al., 2010) , and one includes some people with cognitive impairment (Milte et al., 2015). Seven studies represent some participants living in extended care settings (Clarke and Davey, 2004, Godwin, 2014, Hirschman et al., 2005, Kjellberg, 2002, Milte et al., 2015, Smebye et al., 2012, Span, 2016, Tyrrell et al., 2006), whilst the majority (n=12) relate to people living at home. Of the 19 studies included, only two studies specified *shared decision-making in extended care settings* as their explicit focus (Clarke and Davey, 2004, Godwin, 2014).

The majority of studies (n=15) employed interviews and/or observations (see *table 3*). Three of the linked studies used structured interviews and compared the views of people living with a cognitive impairment and their care partners (Feinberg and Whitlatch, 2002, Menne, 2008, Whitlatch et al., 2005). One study, used structured observations of family meetings (Milte et al., 2015). Three studies undertook ethnographic observations of people living with dementia within a care dyad or triad (Boyle, 2014, Clarke and Davey, 2004, Smebye et al., 2012). Four studies identified person centred care as a theoretical framework (Boyle, 2014, Godwin, 2014, Murphy and Oliver, 2013, Span, 2016).

A breakdown of whether studies aimed to understand, evaluate interventions or measure shared decision-making is presented in *table 3* and discussed within the narrative below. Results are presented in cross-cutting themes that explore decision-making participation or involvement for people living with a cognitive impairment in terms of; how shared decision-making is understood and how participation in decision-making is measured, facilitated and inhibited.

Results are presented to reflect relevance to the review question and objectives rather than frequency that the topic arises in the data (Braun and Clarke, 2006).

Understanding 'shared decision-making' for people living with cognitive impairment

There was no common understanding of what shared decision-making entails and how it can be operationalised for people living with a cognitive impairment. Only one paper offered a definition of shared decision-making. Defining it as an approach that involves patients in making medical decisions with their clinician (Elwyn et al., 2010), is influenced by the type and complexity of the decision being made and the perspectives of care partners as well as the person living with cognitive impairment. Three ways that people living with dementia understand shared decision-making were identified in a phenomenological study (Fetherstonhaugh et al., 2013); subtle support versus taking over; hanging on versus letting go; and being central versus being marginalised or excluded. One participant described their negative response to being excluded;

> *"…if someone came in and started telling me how I should run things or do things, I think I would certainly retaliate and not conform to anything they would want to do."* (Fetherstonhaugh et al., 2013 p.147).

A recurrent theme in the qualitative literature reviewed is that for many people living with dementia, it is the participation or 'sharing' in the decision-making process, that is as, (if not more) important than making the decision itself (Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Horton-Deutsch et al., 2007, Tyrrell et al., 2006). Despite this Samsi and Manthorpe (2013) identified examples of 'substituted decision-making' that essentially excluded the person living with dementia;

“Oh I don't ask her what she wants anymore. I know what she'll say anyway - ‘anything you like, you decide’, so I just do what's best for us both.” (Samsi and Manthorpe, 2013 p.958)

Table 3 - Characteristics of included studies

Author(s) (year) and [reference No.]	Purpose of study	Country	Methods	Quality score	Setting	Participants	Sample size				Results or Outcomes
							PLWCI	CP	CW	Total	
(Clarke and Davey, 2004)	To influence SDM	Australia 3	Qualitative Interviews and observations	75 %	extended care	PLWD and CW	13		13	26	4 positive and 5 negative carer characteristics were identified that impacted on decision-making.
(Fetherstonhaugh et al., 2013)	To understand SDM		Qualitative Interviews	80 %	home	PLWD		6		6	3 pairs of conflicting attributes identified: 1) subtle support versus taking over; 2) hanging on versus letting go; and 3) being central versus being excluded
(Milte et al., 2015)	To understand SDM		Quantitative Observed family meetings	83 %	intermediate care	Older people, CPs and HCPs	51	51	2	104	Geriatricians' performance in SDM was mixed; above baseline skill level in some areas and below in others. Longer meetings = better SDM by clinicians.
(Tyrrell et al., 2006)	To measure SDM	France 1	Qualitative Interviews	83 %	home	PLWD and care partner	21	21		42	PLWD did not feel listened to and had limited freedom to participate in decision-making. Carers were more satisfied than PLWD
(Span, 2016)	To facilitate SDM	Holland 1	Qualitative Interviews, focus groups, specialist consultation and workshops	75 %	home	PLWD, CPs and HCPs				84	18 topics of problems and 8 topics addressing decision-making in emerged. Only 8 topics were identified by both PLWD and Care partners

(Smebye et al., 2012)	To understand SDM	Norway 1	Mixed methods Interviews and observations	95 %	home and extended care	PLWD, CPs and HCPs	10	10	10	30	Care staff do not base mental competence on standardized tests; values and relationships as important as logic. New decision-making categories emerged. Autonomous decision-making occurred but SDM was most typical.
(Ferm et al., 2010)	To facilitate SDM	Sweden 2	Mixed methods Interviews	95 %	home	PLW HD	5			5	Talking Mats increased communication but effectiveness depended on conversation topic.
(Kjellberg, 2002)	To understand		Qualitative Interviews	70 %	home, extended and day care	People living with LD	23			23	Of the 9 theoretical combinations of levels of decision-making identified only 5 emerged.
(Bailey et al., 2011)	To measure SDM	United Kingdom 5	Quantitative Electronic decision-making tasks and questionnaire	79 %	Day services	People living with LD	24			24	Decision-making task performances improved when using the visual aid designed. Although not sustained without the visual aid the improvement was regained when the aid and was reintroduced.
(Boyle, 2014)	To measure SDM		Qualitative observation and interviews	85 %	home	PLWD and CPs	5	5		10	Identified that agency related to SDM is demonstrated within six relevant themes
(Godwin, 2014)	To facilitate SDM		Mixed methods Consultation	90 %	extended care	PLWD	34		42	76	Residents were able to demonstrate preferences relating to their environment and enjoyed the consultation process.
(Murphy and Oliver, 2013)	To facilitate SDM		Mixed methods Researcher facilitated discussion	65 %	home	PLWD and CPs	18	18		18	Participants felt more involved in discussions when using Talking Mats although feeling of involvement was significantly higher for carers than for PWLD

(Samsi and Manthorpe, 2013)	To understand SDM		Qualitative Interviews	90 %	home	PLWD and CPs	15	15		30	3 underlying principles identified of decision-making is negotiated and how dynamics changed: Importance of autonomy, decision specific approach and made on someone's behalf described as' best interest'.
(Feinberg and Whitlatch, 2002)	To measure SDM	United States of America 6	Quantitative Interviews	80 %	home	PLWD and CPs	51	51		102	Lower income and carer financial strain correlated with how well the PLWD felt their carer knew their care wishes (more financial strain = less understanding)
(Hirschman et al., 2005)	To understand SDM		Interviews	70 %	Home and extended care	PLWD and CPs	48	48		96	Spousal carer - wife (90%) vs husband (21%). Half care partners of PLWD formally 'lacking capacity' still involved them in decision-making.
(Horton-Deutsch et al., 2007)	To understand SDM		Mixed methods Interviews	85 %	home	PLWD and CPs	20	20		40	75% PLWD had always involved HCP and/or spouse in decisions. 50% PLWD decisions changed 80% in line with CP wishes. Only 55% of dyads congruent throughout. 20% PLWD maintained choice.
(Menne, 2008)	To measure SDM		Quantitative Interviews Demographic information inc. MMSE scores	100 %	home	PLWD and CPs	217	217		434	PLWD consistently considered themselves to have more involvement in decision-making than their care partners perceived them to be
(Menne and Whitlatch, 2007)	To measure SDM		Quantitative Secondary data analysis	86 %	home	PLWD and CPs	215	215		430	Greater decision-making involvement associated with younger, female, educated, non-spousal CP, fewer months since

											diagnosis, fewer problems with ADLs, fewer depressive symptoms, and place more importance on autonomy/self-identity
(Whitlatch et al., 2005)	To measure SDM		Mixed methods Interviews	100 %	home	PLWD and CPs	111	111		222	Values and preferences correlated with CP perceptions of PLWD quality of life and involvement in decision-making and with PLWD perception of own quality of life and involvement in decision-making.

HD – Huntington's Disease, SDM – shared decision-making, PLWCI – person living with cognitive impairment, PLWD – person living with dementia, LD – Learning disability CP – care partner, CW –care worker, HCP – health care professional

Participation in decision-making

The extent to which a person living with dementia is able to participate in decision-making was a focus of many of the included studies. For the purpose of this paper participation in decision-making is subdivided into the degree or level of participation, ability to participate and desire to participate.

Levels of participation in decision-making

Five studies addressed levels of participation (Horton-Deutsch et al., 2007, Kjellberg, 2002, Samsi and Manthorpe, 2013, Smebye et al., 2012, Tyrrell et al., 2006). Smebye and colleagues used Thompson's five point taxonomy of patient involvement and participation in health care consultations (Thompson, 2007). Thompsons taxonomy ranges from entirely passive 'non-involvement', through cooperative 'shared decision-making', to independent 'autonomous decision-making' (Thompson, 2007). Smebye identified two additional elements through care triad observations and interviews; pseudo-autonomous, (assumptions about a person's decision) and delegated (the person living with dementia expressly delegates their decision-making) when including people living with dementia in care triads (2012). This extended taxonomy is reflected in all five studies exploring the extent of decision-making participation.

Shared-decision-making was considered as the most common decision-making pattern by people living with a cognitive impairment. Horton-Deutsch and colleagues (2007) explored self-reported participation in decision-making for 20 people living with dementia and their care partners' using semi-structured interviews and a five point decision making scale centred on a treatment vignette. The scale ranged from (1) made decisions alone in the past with little input from others and continue to do so, to (5) discussed decisions with spouse in the past and continues to do so. Participants reported that although their self-perceived decision-making changed over time from, largely independent historically towards current interdependent (shared) decision-making, the majority (75%) of participants described some level of shared decision-making throughout (Horton-Deutsch et al., 2007). Similarly, in a group of 23 people living with varying levels of learning disability, 70% rarely considered themselves entirely independent and relied on shared decision-making in some or all areas of their life (Kjellberg, 2002).

Ability to participate

Seven studies (Bailey et al., 2011, Boyle, 2008, Clarke and Davey, 2004, Feinberg and Whitlatch, 2002, Hirschman et al., 2005, Menne, 2008, Whitlatch et al., 2005) explored individuals' ability to participate in decisions often in the context of facilitators or barriers (e.g. Clarke and Davey, 2004). All the studies presenting measures of decision-making participation compared the responses of the person living with a cognitive impairment with their care partners. They highlighted consistent incongruence between responses, with care partners typically believing the person living with dementia to be less involved than they perceived themselves (Hirschman et al., 2005, Whitlatch et al., 2005).

Five papers describe and/or evaluate tools that measure aspects of decision-making participation from the perspective of the person living with a cognitive impairment (Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Godwin, 2014, Horton-Deutsch et al., 2007, Tyrrell et al., 2006). The linked studies (with an overlapping sample ranging from 51-217 care dyads) develop, use and evaluate the Decision Control Inventory (DCI) and the Decision-Making Involvement Scale (DMI) to assess and compare everyday care choices of both the person living with a cognitive impairment and their care partner (Feinberg and Whitlatch, 2002, Menne and Whitlatch, 2007, Menne, 2008, Whitlatch et al., 2005). The DMI Scale measures involvement in everyday decisions such as what food to eat and when to go to bed. It aims to increase participation through communication and improve care planning (Whitlatch et al., 2005). The DCI explores the abilities of people living with dementia to control everyday decision-making preferences. The majority of the findings are however, about home based care identifying that care partners were chosen as primary substitute decision-makers, but financial strain was correlated with how well people living with dementia felt they were understood (Feinberg and Whitlatch, 2002, Menne and Whitlatch, 2007, Menne, 2008).

Decision-making participation characteristics were explored in a qualitative study of 21 care dyad interviews with older people living with dementia and their care partners (Tyrrell et al., 2006). Aspects explored were; information received, being listened to, ability to express an opinion, time allowed for reflection, and opportunity to change the decision. People living with dementia felt that they were not given enough time to reflect on decisions and did not feel their views about care provision were listened to. Care partners reported greater satisfaction with the quality of the communication and decision-making process (Tyrrell et al., 2006).

Only one study explored the person living with dementia's *desire* to participate in decision-making (Hirschman et al., 2005). Using a vignette, the study examined whether 48 people living with Alzheimer's disease would wish to participate in the decision to take a disease slowing medication, and what factors (including family,) influenced their participation. In total 92% of people living with dementia wanted to participate in the decision, whilst only 71% of their care partners thought they would. People living with dementia concentrated on *involvement* in the *process*, whilst their care partners focused on their relatives' *capacity* to participate. Paradoxically, half of the people living with dementia that were formally assessed as lacking capacity (n=29) had care partners who said their relatives would be involved in decision-making (Hirschman et al., 2005).

Facilitators and inhibitors of shared decision-making

Care Partners and professionals

Where roles in decision-making are grounded in 'relationships' (or connectedness), the roles of care partners and workers can be facilitators or barriers (see e.g. Clarke and Davey, 2004, Fetherstonhaugh et al., 2013, Horton-Deutsch et al., 2007, Samsi and Manthorpe, 2013).

Only one study explicitly raised the question of who should participate in decision-making and what their roles should be (Span, 2016). Yet the impact of the relationship between the person living with dementia and their care partner on decision-making involvement is well documented (Boyle, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Menne, 2008, Samsi and Manthorpe, 2013). There is little research focussing on shared decision-making relationships in extended care setting with the majority being undertaken in care dyads within the home environment (see e.g. Miller et al., 2014, Taghizadeh Larsson and Österholm, 2014).

Clarke and colleagues (Clarke and Davey, 2004) observed that care workers' characteristics could facilitate or inhibit decision-making involvement for people living with dementia in extended care settings. Positive characteristics included warmth, encouragement with memory, and routine. Routine also featured as a negative characteristic if linked to task orientated care. An example is given of a resident who appeared to be asleep and the carer had the person's feet out of bed before explaining what they intended to do (Clarke and Davey, 2004 p20). Other negative characteristics inhibiting shared decision-making were: discouraging independence, depersonalisation and risk adversity. The researchers observed more negative incidents than positive ones and felt that residents' autonomy was compromised (Clarke and Davey, 2004). Opportunities for expression of choice were reported to be reduced with the increase of daily care needs in extended care environments (Godwin, 2014, Kjellberg, 2002). Three studies identified reduced shared decision-making associated with: social attitudes, lack of available choices, systems, and care partners and workers identifying more problems than opportunities to involve the person living with dementia (Kjellberg, 2002, Smebye et al., 2012, Span, 2016). Optimal decision involvement was achieved by recognising the abilities and rights of the person living with a cognitive impairment as capable of influencing the decision, giving and sharing information, offering support and reinforcing opinions (Boyle, 2014, Smebye et al., 2012, Tyrrell et al., 2006).

Tools and resources

Four studies developed and/or evaluated the use of tools and resources to facilitate shared decision-making for someone with cognitive impairment (Bailey et al., 2011, Ferm et al., 2010, Murphy and Oliver, 2013, Span, 2016). Two studies evaluated the use of Talking Mats (TMs) which are a picture based, communication framework that allow people to indicate their feelings within a given topic by placing the relevant image on a visual scale. The first study compared TMs with structured and unstructured communication methods with five people in the late stages of Huntington's disease (Ferm et al., 2010) and the second study compared TMs to usual communication methods with 18 people living with dementia and their care partners (Murphy and Oliver, 2013). Both studies reported improvements in satisfaction with discussions when using TMs, although in one study (Murphy and Oliver, 2013) the feeling of involvement was significantly higher for the carers than for the people living with dementia.

Two studies developed computerised tools to support shared decision-making (Bailey et al., 2011, Span, 2016). Span and colleagues (Span, 2016) co-designed an interactive web based tool to promote remote involvement of people living with dementia and their care partners in decision-making around such topics as; social contacts and daily activities, mobility and safety, future care, and finances (Span, 2016). Bailey and colleagues (Bailey et al., 2011) created a visual aid for people living with a learning disability to facilitate participation in decision-making by presenting different types of information in a uniform format. They argue that this uniformity throughout a decision process could support everyday choices. The participants with a learning disability were trained to use the visual aid and their level of decision-making involvement improved as a result, although ongoing use was required to maintain the improvement (Bailey et al., 2011).

Benefits of shared decision-making for people living with a cognitive impairment

Consulting residents living with dementia in an extended care environment, about the care home décor, Godwin (2014) noted as an ancillary finding that residents appeared to be “surprised and pleased” to be asked (Godwin, 2014 p. 114), arguing that this kind of consultation could enhance their self-esteem and contribute to their quality of life. Whilst this study did not measure the impact of the decision-making process, other studies have identified such benefits as heightened self-esteem, purpose and feeling of self-worth, as outcomes from retaining involvement in decision-making (Fetherstonhaugh et al., 2013). Ongoing decision-making involvement for people living with dementia is also correlated with reduced depressive symptoms and maintained everyday functioning (Menne and Whitlatch, 2007).

A rerun of the searches revealed three additional potentially relevant papers (Groen-Van De Ven et al., 2017, Mariani et al., 2017, Society;, 2017), however the Alzheimer’s Society report (Society;, 2017) did not focus directly on shared decision-making. The qualitative study appraising how people living with dementia make decisions about daycare (Groen-Van De Ven et al., 2017) confirmed the findings of the review in noting the crucial role that professionals can play in facilitating shared decisions. This work appears to be linked with an included study (Span, 2016) and would suggest that while there is an ongoing interest in this topic intervention based work in care home settings remains limited. The study dedicated to shared decision-making in dementia care in care homes (Mariani et al., 2017) is relevant however this paper reports only on the care staff perspective of the implementation of the study, and so does not meet the criteria for this review.

Discussion

The available evidence suggests that people living with cognitive impairment want the opportunity to participate in decision-making about their health and care; it can contribute to a sense of worth and has the potential to improve quality of life (Fetherstonhaugh et al., 2013, Hirschman et al., 2005, Tyrrell et al., 2006). A lack of opportunity to participate in decision-making is a significant and consistent barrier throughout the literature reviewed (e.g.

Clarke and Davey, 2004, Kjellberg, 2002, Milte et al., 2015, Smebye et al., 2012). This may be due to confusion about what shared decision-making is in everyday care for people living with cognitive impairment and whether it is in fact opportunities for greater choice that are required. Or it may be professionals' lack of skills in recognising and facilitating peoples' desire and ability to make a decision (Milte et al., 2015). People living with dementia concentrated on *involvement* in the decision-making *process* (Fetherstonhaugh et al., 2013, Hirschman et al., 2005, Tyrrell et al., 2006) but there is a lack of evidence about how the person living with cognitive impairment chooses who they make decisions with and which resources or tools could facilitate people living with a cognitive impairment to *lead* the conversations.

Practical interventions to support and facilitate various aspects of the decision-making process (such as TMs and computer software tools) are reported as having good outcomes for the person living with a cognitive impairment, their care partner and in some cases their health or care professional too (Bailey et al., 2011, Ferm et al., 2010, Murphy and Oliver, 2013, Span, 2016). However, current tools predominantly rely on the care partner or professional to identify the decision topic, potentially disempowering the person living with a cognitive impairment. In addition implementing shared decision-making resources in extended care environments would require care workers being given the time, resource and authority to develop the skills required to use such aids. The included studies fail to provide evidence or discussion of the cost implications associated with embedding shared decision-making for people living with cognitive impairments, or the staff development needed to implement everyday decision-making in extended care settings.

Whether the importance of interdependent relationship between the (family) care partner and the person living with dementia in facilitating or inhibiting shared decision-making at home (Boyle, 2014, Hirschman et al., 2005, Horton-Deutsch et al., 2007, Menne, 2008, Samsi and Manthorpe, 2013) is reflected by the relationship between the person living with dementia and their care staff in extended care settings is not yet understood. However, the frequent underestimation of care partners and workers of the desire and ability of people living with moderate and severe dementia to express preferences about their daily care (Horton-Deutsch et al., 2007, Kjellberg, 2002, Samsi and Manthorpe, 2013, Smebye et al., 2012, Tyrrell et al., 2006) combined with the incongruence in levels of satisfaction in the decision-making process between care partners and people living with dementia (Hirschman et al., 2005, Tyrrell et al., 2006, Whitlatch et al., 2005) raises concerns about the role of consultees under the Mental Capacity Act (2005) (Department of Constitutional Affairs, 2005) in the United Kingdom. Although as the process of decision-making may be as important as the decision itself (Feinberg and Whitlatch, 2002, Fetherstonhaugh et al., 2013, Godwin, 2014, Horton-Deutsch et al., 2007, Tyrrell et al., 2006), it could be argued that if all parties *perceive* that they have optimum levels of involvement and the desired outcomes are achieved the shared decision-making process is a success.

From the limited evidence available on how relationships in extended care affect shared decision-making it appears that how care staff engage is crucial. They can be enablers or blockers to shared decisions, and this appears to be related to their personality, communication skills and the routines of the workplace (Clarke and Davey, 2004, Godwin, 2014, Milte et al., 2015). The implications of the relationships between people living with dementia in extended care and their care staff become increasingly significant as the dementia progresses with care needs increasing and communication capabilities dwindling. A greater understanding of the decision-making needs of the person living with dementia in extended care, and how they can be met, is therefore needed.

Strengths and Limitations

The review involved a systematic and rigorous search for literature relating to shared decision-making for people living with cognitive impairment in extended care settings. As such, this review provides a baseline to inform future research and practice. However, the majority of studies were conducted in the community rather than in extended care settings, quality was variable and there is little evidence on what supports the negotiation of day-to-day decisions between people with a cognitive impairment and their (staff and family) carers in extended care.

The review highlights the difficulties defining what is meant by shared decision-making for people who are cognitively impaired. It is recognised that terminology varies across Countries, disciplines and professions potentially impacting on the studies retrieved. Including additional search terms around ‘choice’ may have identified additional relevant papers that were not identified from terms relating to shared decision-making.

Quality assessment of qualitative studies was changed from the protocol (Daly et al., 2016a) due to access issues so the QualSyst tool (Kmet et al., 2004) was used. This tool has limitations particularly related to lack of requirement to assess an ethics statement.

Conclusion

What constitutes shared decision-making in everyday care for people living with cognitive impairment in extended care remains unclear, which in turn leads to confusion about how to embed the process of shared decision-making into everyday practice in extended care. The significance of the interdependent relationships between people living with dementia in extended care and their care staff develops as dementia, care needs and communication difficulties increase. But whether declining health and function are real or perceived barriers to decision participation remains to be determined, along with the impact everyday shared decision-making would have on the quality of life of people living with dementia in care homes.

People living with cognitive impairment value opportunities to be *involved* in everyday decision-making about their care and involvement in the decision-making process appears to be as important as the decision itself. This desire to share in decision-making is consistently underestimated by care partners and workers, which could have implications for the application of the Mental

Capacity Act (2005) in practice. Tools and resources are shown to have a positive impact on decision-making participation, however in most instances, they do not empower the person living with a cognitive impairment to lead the decision.

Further research is required to understand how opportunities for shared decision-making are created, recognised and understood; and whether they could improve the quality of life for people living with dementia in care homes. Research exploring the relationship between the person living with dementia and their care staff would improve understanding of how shared decision-making can be better facilitated in extended care environments.

Patient and Public Involvement

The research question and systematic review objectives were presented to the members of the University of Hertfordshire Public Involvement in Research Group (UH PiRG), some of whom have experience of caring for family members with dementia. The group advised on the study design. The results of the review and the resulting study will be presented to the UH PiRG at one of their regular meetings.

Authors' contributions

RD wrote the protocol, undertook data extraction, quality assessment and analysis and wrote the paper. FB and CG supervised and critically appraised all aspects of the process. Important changes from the protocol have been explained. All authors read and approved the final manuscript. The authors are grateful to members of the UH PiRG for their input into the design of this review.

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Competing Interests

Authors declare that they have no competing interests.

Data Sharing Statement

No additional unpublished data are available for this review.

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Appendix 2 - Shared decision making for people living with dementia in extended care settings: protocol for a systematic review.

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Tables – 2

References – 41 (inc. statute)

Supplementary files – PRISMA-P checklist

ABSTRACT

Introduction - Approximately 450,000 people in the United Kingdom are living in care homes, 70% of whom are thought to have dementia or significant memory problems. This means that they may need support with day-to-day decisions about their health and care. Shared decision-making interventions can have a positive impact on patient outcomes. They recognise an individual's rights to make decisions about their care or treatment and support person-centred approaches to care delivery.

Method – A systematic review of studies designed to assess, implement, measure and/or explore shared decision making with cognitively impaired adults in (or transferrable to) an extended care setting; with a view to answering the research question: How can people living with dementia and cognitive impairment be included in day-to-day decisions about their health and care in extended care settings? The systematic review will be commenced in May 2016. Studies are excluded that focus on advance decision making. The search strategy is limited to a 20 year timeframe and English language and includes electronic databases; CINAHL, PubMed, the Cochrane Library, NICE Evidence, OpenGrey, Autism Data, Google Scholar, Scopus and MedicinesComplete.

Ethics and dissemination – ethical approval not required. Planned dissemination routes for protocol and systematic review through conference presentations, peer reviewed journals and research networks including the East of England CLAHRC, INTERDEM, and the National Care Homes Research and Development Forum.

Discussion – The review will explore how shared decision making is characterised and constructed in extended care settings for people living with cognitive impairment and their staff and family carers, in relation to their preferences and desires, the roles people play, facilitators, barriers, risk and benefits. The findings will inform an intervention study facilitating shared decision making for people living with dementia in care homes and have the potential to inform future policy and practice.

Article summary - Strengths and limitations of this study include;

- Provision of a contemporary synthesis of evidence relating to recognised risks and benefits of Shared Decision Making for people with a cognitive impairment and their carers in extended care environments.
- Creation of a robust interdisciplinary baseline outlining existing resources, tools and methods used to understand, facilitate and promote shared decision making for people living with a cognitive impairment in extended care settings.
- Reporting bias at study level, e.g. unsuccessful implementation studies are less likely to be published.
- Bias related to data extraction techniques, analysis or reporting methodologies at outcome level and potential inability to retrieve all relevant research due to the search strategy design.

Registration - this protocol is registered with PROSPERO international prospective register of systematic reviews registration number CRD42016035919.

Keywords - Shared decision making, cognitive impairment, dementia, care homes, extended care, everyday care, day-to-day care

Word Count – 3,169

Background

Despite increasing international recognition of the need for shared decision making in health and social care, and its potential impact on quality of life and the global health economy (Stiggelbout et al., 2012) there is limited evidence of how it is used to support people living with dementia in care homes (Smebye et al., 2012).

This protocol defines each element in turn; dementia, extended care and shared decision making before discussing the complex concept of shared decision making for people living with dementia in extended care environments, and the factors that are known to influence it. Gaps in current knowledge will be identified along with how the review proposes to address those gaps.

Dementia

Dementia describes a collection of symptoms that present when the brain is affected by disease processes that include, for example, Alzheimer's, Lewy Body or vascular dementia. Symptoms are degenerative and individual but typically may include memory loss, personality changes and difficulties with word finding or problem-solving. For people over 55 years of age dementia is more feared than any other health condition including cancer and diabetes(Alzheimer's Research, 2015). There are estimated to be 850,000 people living with dementia in the UK, rising to over 1 million in 2025 and 2 million by 2051 (Prince et al., 2014).

A psycho-social theory of dementia frames how the involvement of people living with dementia is viewed, recognising the importance of personhood, and that social and relational losses (not only progressive cognitive impairment) can diminish the personhood and self-worth of those living with dementia (Brooker, 2004, Kitwood and Bredin, 1992).

Extended Care Settings

For the purposes of this review the term ‘extended care setting’ is used to include all types of residential housing with onsite care provision. In addition to care homes, extended care settings include supported living, care villages and extra care housing. Approximately 450,000 people live in care homes in the UK (Demos, 2014) and Prince et al. estimate that around 70% of care home residents in the UK have dementia or significant memory problems; as a result this population may need support and assistance with decisions about their day-to-day health and care.

Shared Decision Making

Shared decision making is a partnership which enables clinicians and patients to make health and care related treatment, management or support decisions based on best available clinical evidence and the patient’s own values and preferences. It involves eliciting the patients ideas, concerns and expectations (Stiggelbout et al., 2012) and the provision of evidence-based information about options, outcomes and uncertainties. (Coulter and Collins, 2011).

Decision support tools or aids clarify available treatment options, including possible harm and benefits, and support people to work with professionals to choose a course of care that reflects their personal values. Internationally a variety of tools have been developed to support Shared Decision Making (Healthcare;, 2016, National Health Service, 2012, Quality;, 2015) especially in relation to specific healthcare screening and interventions (Frosch et al., 2011, Holmes-Rovner et al., 2000, Légaré et al., 2007). Shared decision making has been recognised as having a positive impact on a range of patient outcomes (Coulter and Collins, 2011, Durand et al., 2014, Miller et al., 2014).

This review will explore the role of shared decision making in day-to-day health and care decisions between (staff and family) carers and people living with dementia in extended care settings. For example, this might include decision making about personal care preferences, medication regimes, or the timing and approach to changing a wound dressing. Some of these more seemingly trivial decisions need to be faced each day and for a person living with dementia who may be dependent on help and support from others to fulfil their care needs and desires, *how* decision making is approached, understood, and negotiated that can be indicative of the impact on their personhood. The opportunities for choice and control and the perceived risks and benefits of any given decision may be largely dependent upon the relationship between the person living with dementia and their carers (Smebye et al., 2012, Stiggelbout et al., 2012).

Central to the topic of shared decision making for a person living with dementia is their ability to make their own decision, either with or without support. Successful shared decision-making assumes that care receivers are informed, empowered and enabled to participate in discussions about their health and care. It requires them to have developed the skills, knowledge and confidence required to discuss their options with experts, challenge professional views, and influence their care and outcomes (Durand et al., 2014). This may prove a significant challenge for individuals living with dementia. The possibilities for, and appropriateness of, shared decision making for people with cognitive impairments has been researched within the field of acute mental health and there is evidence of positive outcomes for all involved, including improved knowledge, wellbeing and medication adherence in addition to reduced conflict (Adams and Drake, 2006, Deegan and Drake, 2006, Stein et al., 2013).

The historical assumption that people living with a cognitive impairment cannot participate in decision making is increasingly being challenged and an individual living with a cognitive impairment’s ability to maintain active participation in decisions about their health and care has caused considerable debate (Dresser, 1995, Dworkin, 1993, Jaworska, 1999). In practice, many settings rely upon family members to make care decisions for people living with dementia, often regardless of individual’s currently stated preferences, legal, medical, or ethical processes (Miller et al., 2014). In their review of international literature on patient and carer involvement in shared decision making for people living with dementia, Miller, et al. acknowledged that research in this area of practice is relatively new, however they identified multiple sources of evidence which indicates that people with dementia can reliably report on their ideals and preferences in relation to their care, well-being, and quality of life, even through moderate to severe dementia. Therefore, whilst family carer involvement is essential it should be sought as a partner and not to supersede the views of the person living with dementia. The review focussed on shared decision-making within ‘family care dyads’ in the community (comprised of a person with dementia and a family carer) although care dyads might equally comprise a health or social care professional and a person living with a cognitive impairment. Regardless of the other parties involved, the person living with the cognitive impairment must, at least, be given an opportunity to choose to participate in the decision making process (Miller et al., 2014). Furthermore, many people living with dementia maintain their ability to communicate their values and preferences albeit through verbal, non-verbal and tailored communication aids, long after their executive decision-making ability is affected by cognitive decline (Miller et al., 2014).

Extensive work undertaken in the UK by the Dementia Action Alliance (Alliance;, 2009) has identified that people living with dementia want personal choice and control in decisions that affect them, and to know that services are designed to meet the needs of themselves and their carers. Person centred care is now widely accepted as the method for ensuring individuals are involved in planning and designing their own care and is an ethical and legal requirement throughout Europe, Australia and North America (Edvardsson et al., 2010, Hutchison et al., 2011, Stiggelbout et al., 2012). It is also embedded in UK national policy and health and care regulations (MCA, 2005; DH, 2010; Care Act, 2014) and international guidance (World Health Organization, 2015). To abide by the law and fulfil the moral obligation to provide person centred care it is important to have an understanding of each person’s needs and desires and, where possible, to include them in all the decisions that shape their care. This is reflected in the drive for improved treatment of people living with dementia and their carers (Prince et al., 2014) and greater involvement in the decisions central to their care (Department of Health, 2012b).

Method

The review will be conducted utilising methods outlined in the Cochrane handbook of systematic reviews of interventions (Higgins and Green, 2008b). This protocol has been designed in accord with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-P) guidelines (Moher et al., 2015)and checklist (supplementary file 1). The protocol is registered with

PROSPERO international prospective register of systematic reviews registration number CRD42016035919.

The aim of the review is to understand how day-to-day decisions are negotiated between people with a cognitive impairment and their (staff and family) carers in extended care settings, with a view to gaining transferrable learning that can be applied to people living with dementia in care homes.

The review objectives are to;

- Explore how shared decision making is understood and/or characterised for people living with dementia and their (staff and family) carers.
- Explore the role of (staff and family) carers of people living with dementia in shared decision-making care dyads.
- Analyse identified risks and benefits associated with shared decision making for people with cognitive impairment
- Ascertain empirical evidence for the effectiveness of available shared decision-making resources for people living with dementia
- Seek to understand the barriers and facilitators to effective shared decision-making for people living with dementia and their (staff and family) carers
- Explore the extent to which shared decision-making has been researched in extended care settings
- Identify implications for shared decision-making in dementia care practice, policy and future research

Inclusion criteria

Participants

The focus of the review is adults, over 18 years, living with any type of dementia in an extended care setting. Studies relating to adults with other cognitive impairment (for example; learning disability or brain injury) will be included where the model, tools or intervention are transferable to people living with dementia in an extended care setting. To be considered transferrable the person living with a cognitive impairment must be in receipt of care in addition to their family carer and the intervention, measure, resource or method should be able to be practically implemented within an extended care setting. Authors will discuss and agree by consensus if there is any doubt regarding the inclusion of any paper.

Setting

The term ‘extended care setting’ is used to include all types of residential housing with onsite care provision. The UK Care Quality Commission define care homes as offering ‘accommodation and personal care for people who may not be able to live independently’ and register care homes ‘with’ and ‘without’ nursing(Care Quality Commission, 2009). Studies in other settings, e.g. people’s own homes, will be included if they meet all other inclusion criteria and are transferable to an extended care setting.

Interventions

Studies will be included if they report primary research designed to assess, implement, measure and/or explore shared decision making with cognitively impaired adults. With particular focus on interventions relating to day-to-day health and/or care decision-making (for example decisions relating to personal care or medication management).

Exclusion criteria

Papers specific to advance decisions or advance care planning will be excluded as these reflect the person making decisions about future care whilst they are still considered to have capacity and the focus of this review is on current day–to-day care being delivered to the cognitively impaired person. Studies where the shared decisions are made primarily by health or social care staff and, or family carers and do not include the person living with the cognitive impairment will also be excluded. Studies pertaining to participants living with potentially relevant symptoms and/or conditions but without cognitive impairment will be excluded due to the primary focus being on the person living with dementia.

Types of studies

All empirical study types that meet all other inclusion criteria will be included; randomised controlled trials (RCTs), controlled studies, observational studies and qualitative studies using any recognisable qualitative methodology.

Outcomes

- Involvement in care planning (e.g. as stated within care plans)
- Care delivery congruent with decision made/expressed choice (e.g. as stated in daily care records)
- Quality of life for people living with dementia
- Carer satisfaction (staff and/or family carers)
- Wellbeing for people living with dementia
- Behavioural changes (e.g. reduction in behaviours that challenge services)
- Adverse effects (e.g. falls, weight loss, adverse outcomes related to medication management)

Search strategy

The predefined search strategy is cross discipline. Limitations have been set with regard to;

- Time - 20 years (start date 1996) due to the fast-paced nature of treatment and intervention development in this area of care, but to still include the seminal works of Tom Kitwood.
- Language – only studies published in English language will be included
- Free text search terms will be limited to Title and Abstract to promote relevance of search results

Electronic searches will be performed on the following databases; CINAHL Plus, PubMed, the Cochrane Library, NICE Evidence, OpenGrey, Autism Data, Google Scholar, Scopus and MedicinesComplete. In addition the reference list of all relevant primary and review articles will be searched manually to identify studies which have not been picked-up by the electronic search. A citation search will also be performed using the ‘cited by’ option on Google Scholar and Scopus, and the ‘related articles’ option in PubMed.

Medical Subject Heading (MeSH) search terms will be combined with Boolean operators AND, and NOT (between columns) to create a search strategy for PuBMED and other electronic databases which recognise MeSH terms. See *table 1* columns for MeSH headings and alternative MeSH terms combined with OR for an inclusive search strategy. See table 2 for alternative but equivalent free text terms operated with ‘wildcards’ and truncations will be used to search CINAHL and other databases which do not recognise MeSH headings.

Study screening and Data extraction

Electronic search results will be downloaded into EndNote bibliographic software and duplicates removed where possible. Initially all titles and abstracts retrieved by electronic searches will be screened by one reviewer (RD) against the predefined inclusion criteria and a second reviewer (FB) will independently screen 10% of records to check for consensus. Full-text manuscripts of all potentially relevant citations will be obtained. Hard copies will then be screened independently by RD and either FB or CG. Any disagreements will be resolved by discussion and consensus.

Data will be extracted on the following 1) the author(s), 2) publication year, 3) country, 4) type of study design, 5) aim(s) and research questions, 6) type of participants and sample size, 7) data collection method (i.e. measure of Shared Decision-making/patient activation/patient involvement), 8) response rate, 9) method(s) of analysis, 10) outcomes.

Additional information will be collected relating to the accessibility and characteristics of interventions, duration of follow-up and any unexpected supplementary findings/outcomes identified by the researcher.

Quality Assessment

Quality assessment will be undertaken by one reviewer (RD), with 10% checked by a second reviewer (FB/CG). RCTs and controlled studies will be assessed using the Cochrane risk of bias tool (Higgins and Green, 2008a), observational studies using the Centre for Evidence Based Management assessment tool and qualitative studies using JBI System for the Unified Management of the Assessment and Review of Information (JBI SUMARI) - Qualitative Assessment and Review Instrument (Qari) framework, which has been identified as one of the most coherent critical appraisal tools to facilitate an assessment of qualitative research validity (Hannes et al., 2010).

Analysis

Quantitative studies

Results from all studies will be reported in a narrative format. In addition if there is sufficient homogeneity, and if relevant studies are available, RCTs will be pooled in a meta-analysis with dichotomous outcomes presented as relative risks (RR) and continuous data as mean differences (MD), both with 95% confidence intervals. Heterogeneity will be assessed using the Chi-Square test and I^2 test (Higgins and Green, 2008a) . However, in the likely event of heterogeneity (or few RCTs being found) studies will not be pooled but data will be presented in a narrative format with an indication of whether the effect of the intervention was positive, negative or not statistically significant.

Qualitative studies

Review findings will be compiled and evaluated using thematic analysis. This is a widely recognised process (Hannes et al., 2010, Hawker et al., 2002, Mays and Pope, 1995), which involves using recurrent themes in primary studies to synthesise new qualitative evidence (Lewin et al., 2013). All relevant 'data' will be considered for synthesis including those data labelled as quotes, 'findings' and 'results' as per guidance (Thomas and Harden, 2008).

Amendments:

If any amendments to the protocol are required they will be individually described, dated and rationalised to ensure transparency and enable the reader to identify potential bias and to replicate the searches if required.

Discussion

In the UK there are estimated to be 850,000 people living with dementia and approximately 450,000 people living in care homes, the majority of whom have significant memory problems (Prince et al., 2014). An understanding of each person's needs and desires is important to include them in the decisions that shape the decisions about their health and care(Brooker, 2004, Kitwood and Bredin, 1992) which is a moral imperative.

Little is known about how decision making between people living with dementia in extended care settings is shared with their staff and family carers, and further research has been recommended e.g. (Légaré and Witteman, 2013, Miller et al., 2014). With a view to adding to the body of knowledge, this review will build on the evidence about the measures, tools and resources from different specialities and aims to bring together all relevant evidence rather than focussing on any specific field of practice, thereby expediting an integrated and interdisciplinary approach to research into dementia care centring around the individual reflecting the comparable drive in health and social care practice (e.g. WHO global strategy on people-centred and integrated health services)(World Health Organization, 2015).

The systematic review will provide a contemporary synthesis of evidence in relation to the current understanding of Shared Decision-Making policy and practice for people living with a cognitive impairment in extended care settings. It is designed to explore the characterisation and constructs of shared decision making for people living with dementia and their carers recognising relationships in care and how those relationships impact on care choices and decisions. Facilitators and barriers and risk and benefits will be explored in the context of resources, methods and tools in an effort to identify a readily available and financially viable intervention that can be independently trialled with a view to comprehensive and equitable implementation throughout the care sector.

It is recognised that there are potential limitations in relation to reporting bias at both study and outcome level, for example unsuccessful implementation studies are less likely to be published by authors; and at review-level, for example, the inability to retrieve all relevant research due to possible inadequacies in the search strategy; or reporting bias related to data extraction or analysis. In an effort to overcome these limitations the search terms and strategy have been reviewed to facilitate a wider breadth of results (e.g. databases from a number of professional fields and have been searched to allow for publication bias). The findings will inform the design of an intervention study facilitating Shared Decision Making for people living with dementia in care homes and have the potential to inform future policy and practice.

Authors Contributions:

All authors contributed to the selection, bias assessment and data extraction criteria. Statistical expertise will be provided by FB. RD created the protocol with supervision by FB and CG as part of a wider PhD project. RD prepared the search strategy with support from FB and the University of Hertfordshire health information manager. FB and CG critically appraised all drafts and will independently review 10% of all search results to promote consistency with inclusion criteria. All authors agreed the final manuscript.

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Competing Interests

Authors declare that they have no competing interests.

The Care Act, UK (2014) [online] Available at http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf

Equality Act, UK c15 (2010) [online] Available at http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf

The Mental Capacity Act, UK (2005) [online] Available at http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

Abbreviations

CINHAL - Cumulative Index to Nursing and Allied Health Literature

CLAHRC - Collaboration for Leadership in Applied Health Research & Care

DH - Department of Health

INTERDEM - Early detection and timely INTERvention in DEMentia

JBI - Joanna Briggs Institute

MCA - Mental Capacity Act

MeSH - Medical Subject Heading

PRISMA-P - Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Qari - Qualitative Assessment and Review Instrument

SUMARI - System for the Unified Management of the Assessment and Review of Information

UK - United Kingdom

Table 1 – MeSH search terms

Cognition Disorders	**AND**	**(Shared Decision Making)**	**NOT**	**Paediatrics**	**NOT**	**Advance Directives**
Dementia		Decision Making		Children		Advance care planning
Neurocognitive Disorders		Patient Participation				

Brain Injuries	Consumer Participation
Autistic Disorder	Cooperative Behaviour
Learning Disorders	Decision Support
Stroke	

Table 2 – Free text equivalent search terms

Cogniti* Disorder*	**AND**	**Shared Decision Making**	**NOT**	**Paed***	**NOT**	**Advance Directives**
Dementia*		Deci* Mak*		Child*		Advance* care planning
Alzheimer*		Patient Participat*				Advance* deci*
Neurocogniti* Dis*		Consumer Participat*				
Brain Injur*		Cooperat*				
Autis*		Decision Support				
Learning Dis*						
Stroke						

Appendix 3 - Interview/Focus group schedule (Care Worker)

Introduction and gaining consent:

Check Information Sheet has been read and consent form completed (as appropriate).

Thank you for agreeing to take part in this interview. I am interested to find out how you help residents to make decisions about their everyday/day-to-day care. I am particularly interested in your positive experiences of helping people living with dementia and communication difficulties in making day-to-day care decisions. For example; what you think works well, who you help and how. The information will help me to understand how we can help to increase decision-making involvement for more people living with dementia and communication difficulties.

I would like your permission to record this discussion as it is difficult to take detailed written notes as we go along. Everything you say will be confidential to myself and my supervisors. The recording will be written up and any information that might identify you will be removed. I can stop the recording at any time if you let me know. You will not be disadvantaged by stopping the interview. This interview should take less than half an hour. Do you have any questions before we start?

Interview/focus group 1 – Discovery phase

1. **Can you let me know a little about your job/role in this care home?**
    - *How long have you worked here?*
    - *What is your favourite thing about this job?*
    - *Have you worked as a carer before?*

2. **Can you let me know a little about your communication style?**
    - *How do you help your residents with their decision-making? (Using prompts, pictures, actions etc?)*

- *What difficulties do they encounter (e.g. sight, hearing, speech, interpretation etc) and how do you help them overcome those difficulties?*
- *Would you do a mental capacity assessment for an everyday decision and would you normally document it? (This is not a trick question I am just looking for baseline information)*

3. **What type of decisions do you normally help residents make about their care?**
   Prompts:
   - *Do you help them choose what to eat and when to go to bed?*
   - *How do you know when they want to choose and when they want you to make a decision on their behalf?*
   - *How do you help them choose?*
   - *Is understanding them tricky?*

4. **Can you let me know about a recent decision that went really well/made you happy?**
   Prompts:
   - Why do you remember it?
   - What made it special?
   - Who did you help?
   - How did you help?
   - What did you use (tools, aids, personality?)

5. ***Is there anything you would like to add?***

Interview/focus group 2 – Dream phase

Revisit introduction and consent.

1. **Has anything changed since we last met that you would like to tell me about?**

2. **Last time, you shared with me a decision that went really well/made you happy. That was really helpful…**
   Prompts: Use notes from previous interview to remind if necessary and discuss.

3. **To move forward I would like to know, how could you make shared decision-making even better for with memory and communication problems? Pretend that time and money are no object!**
   Prompts:
   - The more creative the better – this is your opportunity to think big!
   - There are no right or wrong answers
   - Who would you involve?
   - Would you use a tool or aid of some sort? What would that look like?

4. ***Is there anything you would like to add?***

Interview 3 – Design phase

Revisit introduction and consent.

1. **Has anything changed since we last met that you would like to tell me about?**

2. **Last time you shared with me how you would make decision-making better for the people you care for with memory and communication problems, in a perfect world where time and money are no object.**
   - Use notes from previous interview to remind if necessary and discuss.

3. **This time, I would like to look at your ideas from last time with some ideas that other people have had. Then I would like you to think about what we can actually make happen with the reality of constraints. We are looking for something practical that really could make decision-making better and easier for you and the people you care for.**
   Prompts:
   - Share other ideas from interviews and focus groups. What is your opinion? What do you like best? What don't you like?
   - Would you like to play an active role in making this happen?
   - What would you like that to be?

4. ***Is there anything you would like to add?***

Interview 4 – Destiny phase

Revisit introduction and consent.

1. **Has anything changed since we last met that you would like to tell me about?**
2. **Last time we discussed how we can make a real difference to everyday care decision-making for you and the people you care for.**
    - Use notes from previous interview to remind if necessary and discuss.
3. **Today I am interested in how you feel about what has happened so far. Have you noticed any real differences in decision-making? If yes, how can we keep this up? If no, what can we do to make it happen?**
   Prompts:
    - If you are taking an active role what has been the best part of that?
    - Is there anything else you think we could do to get even better?
4. ***Is there anything you would like to add?***

In each interview question 1 is about trust and rapport building.

Appendix 4 - Resident information sheet

Would you like to take part in some research?

A student from the **University of Hertfordshire** is doing some **research.** It is **about memory and communication problems.**

Research helps us **learn** about **how to help people living in care homes**

You don't have to decide now, you can **think about it.**

You can **look at the information again.**

You can **ask your family or carer** to **help you decide.**

If anything is unclear, or you would like more information, Rachel Daly will be happy to talk to you (Tel: xxxxx).

Who is doing the research?

The **researcher you will see** is Rachel Daly. She is a PhD student. She is also a nurse.

The research team are based at the **University of Hertfordshire** and Professor Claire Goodman and Dr Frances Bunn are study supervisors.

NHS
National Institute for
Health Research

The **National Institute for Health Research** is paying for this research.

Why me?

You have some **memory and communication problems.**

We would like to **talk to you about** how this affects **your day to day life.**

What is the research for?

We **don't know** enough about **what helps people in care homes** to **be involved in decisions** about their day to day lives**.**

This **research** will help us to **learn more.**
We would like to **understand how** you **make decisions** about your care.

We would like to know **who helps you.**
We are interested in **how they help you.**

We would like to learn from your experiences to help other people with making decisions about their care.

Do I have to take part?

No! You do not have to take part.

If you choose to take part, then change your mind, **you can stop** at any time. You **don't** have to **give a reason.**

If you decide to stop you will still get your **normal help and care.**

What happens in the research?

If you chose to join the research;

You may notice **Rachel** in the lounge or dining room **making notes** about what what she sees and hears.

The **notes will not name people** and are confidential.

Rachel will talk to you about living in a care home.

We will help you with your communication.

She will ask you some questions about how you make decisions.

Your **opinions** and **ideas are important**

There are no right or **wrong answers**.

We will sound **record the interview.**

This helps us to **remember** what you said.

Only the research team will listen to the recordings.

They will be destroyed, **and your name will be taken out** when they are written down.

The research will take place **in your care home.**

We will find a time and place to talk **where you feel comfortable**.

People like you from **2 other care homes have** also **been invited** to take part in the research.

We will keep the **information** about you **safe.**

The researcher will not see you have any personal care or come into your private room unless you invite them.

How long will the research last?

Rachel will visit XX care home on XX and the study lasts for about six months

Each interview will last for **about half an hour**.
It may take more or less time. There will be three or four interviews spread out over the six months

Who will see the information about me?

Only the **researchers** will see all the **information about you.**
No one else will know your name and **personal details.**

The findings from this study will help to improve care for people living in care homes.

What might be good about taking part?

You may be helped by some of the ideas

You may **enjoy** taking part

You may find it **interesting**

You will **help people** in the future

You will **help us to learn**

Will I get paid?

No. You will **not get paid** for taking part in the research

What might be difficult about taking part?

You may find it **tiring or upsetting**

It will **take** up **your time**

What if I don't take part in the research?

You will still get your **normal help and care**

Is the research safe?

An **ethics committee decides if research is safe**.
They say that this research can happen.

They say that it has been planned properly.

It is very unlikely that anything will go wrong.

If you **take part** in the research and **if you think** you were **harmed** there are **people to talk to.**

The University has **insurance.**

Contact Frances Bunn (lead researcher) **on** xxxxx.

If you require independent advice about making a complaint you could contact the Independent Complaints Advocacy Service (ICAS) [XXXX *local address and telephone number]*

What will happen after the research?

The researchers will look at the results.

They will **learn more about memory and communication problems.**

We will give you the results of the research.

We will share the results with other researchers
at conferences and meetings
through newsletters and magazines
in academic journals

The results may include **what you said** but **not who said it.**
The results will **not use your name.**

What next?

You decide if you want to take part.
We will **contact you.**

We will ask for **your decision.**

You may want **more information.**

Rachel Daly will **answer your questions.**

You can **let** Rachel know if you want to take part **when she comes to visit** you at your home.

If you decide to take part you may **sign a consent form.**

This says that **you understand** the research and **you agree** to take part.

You **can still take part** even **if you cannot sign** the form.
We will help you to **take part** if that is what you want to do.

Yes I want to take part in the research.

No I do not want to take part in the research.

If you decide to take part **Rachel will ask** you **for an interview.**

This **interview** will be **at your care home**.
You can **bring your carer or a family member** if you want to.

Please **bring anything** that you use **to help you to communicate**. For example, this might be a **hearing aid, your glasses, a pen and paper, a picture board** or a computer.

How do I contact the researchers?

To contact us use the following details or see Rachel at your care home:

Rachel Daly, PhD Student - Tel: xxxxx Email: xxxxx

Claire Goodman, Professor of Health Care Research - Tel: xxxxx Email: xxxxx

Frances Bunn, Reader in Evidence Based Health Care - Tel: xxxxx Email: xxxxx

Address:

Centre for Research in Primary and Community Care

University of Hertfordshire, College Lane**,** Hatfield, Herts. AL10 9AB

This information sheet was designed using the NIHR CRN Stroke resource ‘Engaging with people who have aphasia’ (Pearl, G. 2014)

Appendix 5 - Observation Schedule

When observing in clinical areas, the following provides a guide for making field notes.

Broad descriptive accounts of interactions between people living with dementia and communication difficulties and care staff will be written only in relation to decision making.

Factual aspects to be documented:

- Date and time of observation
- Gender of the resident and the care worker/partner
- Care home pseudonym
- Location within the home (e.g. lounge/dining room)
- Diagram/description of area being observed
- Decision type (e.g. food, medication, care)
- Who identified the need for a decision?
- If the person living with dementia needed support how was this facilitated (note any tools, equipment or personal characteristics used)
- Number of care staff, partners and residents involved in the interaction
- Note any visitors or other professionals onsite/in the vicinity
- Number of residents in the room

In recording events pay attention to what was done well:

- Physical and verbal communication and interactions between; care workers and people living with dementia, care partners and people living with dementia, and people living with dementia with each other
- Resident, care worker and partner behaviours
- Levels of decision participation for people living with dementia and communication difficulties measured 0-3 against the decision-making inventory (DMI) scale
- How the need to make a decision was recognised and met
- Care home environment and culture
- Evidence of impact of leadership
- Use of communication tools
- Evidence of reflective practice
- Evidence of role modelling

Appendix 6 – Decision making involvement scale

Decision-Making Involvement Scale		
Area of decision making	score (0-3)	Comments/observations
Spending money?		
Visiting with friends?		
What foods to buy?		
When to go to bed?		
When to get up?		
Spare time activities?		
Being physically active?		
Participating in religious/spiritual activities?		
Expressing affection?		
Having a pet?		
What to eat at meals?		
Choosing places to go?		
What clothes to wear?		
Choosing where to live?		
Getting medical care?		
Other (specify)		

Decision making involvement scale (Feinberg and Whitlatch 2002)

Appendix 7 – Care home profiles

Care Home One (Treetops)

Overview

Nursing accommodation for a maximum of 90 service users.

Specialising in

- Care of adults over 65yrs
- Dementia
- Care of adults with learning disabilities

Funding – Not for profit (78% of the beds are currently Local Authority or Continuing Healthcare funded)

Care records – Paper based

The Manager

The registered manager maintains his professional registration and ongoing CPD and encourages the home to participate in research projects that could help enhance the quality of people's care and improve their experience. The registered manager in post has been at the home for a total of 7 years and has been manager for approximately 2 years. He has worked in several roles and staff really like him. Staff appear to know all their residents very well and they proudly offer person centred care.

Training

There is an on-going training programme and staff are encouraged to work towards nationally recognised courses such as Business and Technology Education Council (BTEC) awards. Staff report that training is up to date in all mandatory and core areas including dementia care, medication managements and safeguarding.

Working relationships

The home has a strong working relationship with local GPs and other healthcare professionals.

Staffing

Staff turnover is relatively low, and the manager encourages them to take on additional roles and responsibilities to stimulate their interest. The home always appears to be well staffed and CQC states there are ‘enough staff to meet people’s needs.

Staff are recruited using robust procedures including a panel of residents to ensure that they feel that staff have the right skills and attributes. Staff report that they receive a structured induction and an annual appraisal.

Occupation and activities

People are supported to take part in a wide range of activities including access to the wider community. There is a learning disability unit (a unit within the home but managed separately) and the door between the 2 units is always open and people are encouraged to socialise in the reception area of the home (which also has a coffee bar and a pub).

There is a weekly and monthly activities programme printed and provided and people are encouraged and supported to join in a wide variety of activities.

Staff appear to go above and beyond to fulfil people’s wishes and facilitate and maintain relationships (such as ‘date night’, where the care home invites a resident’s partner in for a candle lit dinner for two, waited on by the care staff. This is done on a rotational basis and to mark special occasions such as birthdays and anniversaries).

Dementia Care

The staff appear to have a strong understanding of dementia care and use music and pictures regularly to aid communication and use their skills where possible to anticipate a person’s needs, read signs of changes in expression or behaviour and preventing a built-up anxieties and frustration.

Activities are planned to be creative and rewarding, as part of group experiences, such as singing, arts and crafts, domestic tasks including baking, and sports – including Boccia.

The Building

The building is purpose built and well maintained although the manager and dementia lead commented that additional work could enhance the environment for people living with dementia (such as contrasting furniture and carpets etc.).

There are 6 units of 15 beds each. 1 unit is specific to learning disability care and 2 units are specific to dementia care (although about 80% of residents in the main home have dementia or symptoms that are reflective of dementia, and about 20% of the learning-disabled residents are thought to be living with dementia too).

The creative themed displays around the building (which are designed to help engage with people living with dementia) include a sweet shop, a post office and a pub.

The home has a safe and secure garden with plenty of seating and a large pergola offering shade and additional seating. In the summer many of the activities are carried out in the garden.

Parent Organisation

The parent organisation is a not-for-profit organisation and where possible works on a ‘home for life’ basis – accepting privately and local authority funded residents. The organisation has award-winning specialist dementia care services led by a highly experienced dementia care professional. Dementia care is person-centred in nature and has an extensive programme of courses available to all staff including an externally accredited BTEC in dementia care course and several 2 and 3 hour practical sessions from a basic level to relatively advanced.

Family involvement

Involvement and cooperation from family and friends is strongly encouraged. They are encouraged to support life story work to enrich residents’ experience.

Daily routine

Morning – people rise whenever they please mostly between 7 and 10.30am (unless they have a time specific medication which influences this such as insulin). They then have breakfast at their leisure which can be prepared on the unit. They can eat in their room or in the dining room. Cooked breakfast is only available from the central kitchen and so is only cooked at a specific time (around 8.30am).

Morning activities

11am - activities (ranging from trips out to card games and coffee mornings, church services and arts and crafts) in a range of locations around the home, garden and some trips out.

Lunchtime – hot lunch served at 1pm. Choice available but limited. Individuals are able to request alternatives to what is on the menu (such as; jacket potato, salad or poached egg on toast).

Afternoon activities – as morning activities

Teatime – soup plus sandwiches and cake

Evening activities – evening activities are ad hoc and are specific to each unit.

Bedtime – people are able to choose when to go to bed and this appears to be anything from about 5pm to 11pm although most people are in bed before 9pm. As this is a high needs nursing home some people are nursed in bed 24 hours a day.

Snacks and ad hoc activities are available throughout the day.

Hairdressers are onsite on Tuesdays and Wednesdays.

What I noticed

The atmosphere at the home feels calm and welcoming. The reception desk is in the foyer along with a coffee bar and the ‘pub’. The room is light and bright with double doors onto the garden. The manager is keen to help and knows every resident and they all know him. He assisted a lady in a wheelchair as we walked past and chatted with a gentleman who was upset, getting down to his level in the chair and really taking time to be with him trying to alleviate his anxiety.

None of the unit doors were locked on my first visit and there was a pleasant buzz of visitors and residents making tea and getting ready to do an activity in the garden. There have been a lot of visitors on site each time I have visited. 2 young volunteers were helping with the activity as part of the DoE award.

Care staff were sitting and chatting and eating with people who needed encouragement to eat making it a social interaction. This was particularly noticeable with people living with dementia who seemed more inclined to eat because someone was with them rather than feeding them.

The care appeared to be compassionate and natural and the manager told me stories to illustrate episodes of care that had struck him. The home appears to use stories, art and music regularly with the residents and are keen to identify anything that they can do differently to improve the care even further. All the staff smiled and said hello as I walked around.

The home has a mixed clientele with a diverse population in terms of age socio-economic status and culture.

Care Home Two (Eden Valley)

Overview

Nursing accommodation for a maximum of 90 service users.

Specialising in

- Care of adults over 65yrs
- Dementia

Funding – Private for-profit organisation (100% of the beds are currently privately funded)

Care records - Electronic

The Manager

The service has a registered manager who has been in post for 7 years since the service opened. He maintains his professional registration and ongoing CPD and encourages the home to participate in a range of projects to enhance the quality of people's care and improve their experience. The clinical lead has also been in post for the same period. The leadership team is strong and well respected in the home by staff and residents and families.

Training

The bespoke training programme is commissioned by the clinical lead. Who tells me that training is up to date in all mandatory areas including dementia care, medication managements, infection control and safeguarding. Staff are encouraged and supported to maintain their professional development and arrangements are made to facilitate this.

Staff training requirements are discussed in supervision and appraisal with their line manager. The service won 'Employer of the Year' from local colleges in recognition of the support and emphasis on training and diplomas. The service offers work placements to professional student nurses and paramedics and college students studying for an HND in health and social care.

Working relationships

The home has a strong working relationship with local GPs and other healthcare professionals, notably ambulance staff and community nurses who are welcomed to come and have coffee when they are on duty.

Staffing

Staff turnover is relatively low, and the manager and clinical lead manage the home like 6 individual homes with the same staff staying on the same unit where possible, to promote continuity. Each unit has its own named nurse, care staff and cleaning staff. The home appears to be well staffed and CQC states there are ‘enough staff to meet people’s needs’.

Residents are encouraged to participate in the recruitment of new staff. Staff receive a structured induction, regular supervision and an annual appraisal. They are well-trained and motivated. Chefs are trained to produce fresh, home cooked, nutritious meals which encourage residents to eat and participate in the social activity of enjoying food.

Occupation and activities

This home has an award winning, highly creative activities programme that includes a carpet bowling league and a gymnasium. One lady hosts her old bridge club meetings in the private dining room. People are actively involved with the local community and encouraged to engage in activities and entertainment available within the service.

Dementia Care

Care staff appear to understand the different types of dementia well. People are supported to have maximum choice and control of their lives and staff support them in the least restrictive way possible; the policies and systems in the service support this practice.

The Building

The building is purpose built and maintained to an exceptionally high standard. The building has been designed to maximise assistive technology and be dementia inclusive, with automatic lights in en-suites. The lounge and dining areas in the dementia units have ‘sunlight’ lighting which is designed to minimise the effects of ‘sundowning’ and minimise shadows.

Facilities include a fully fitted gym, library, an activities room and a private dining room for special family occasions. There is a coffee bar near the foyer that feels like a nice coffee shop where people can meet up with friends and families if they were unable to visit them outside the service.

The home has a safe and secure garden with plenty of seating, to enjoy fresh air and opportunities to undertake outdoor activity.

There are 6 units of 15 beds each. 3 units are specific to dementia care although about 70% of residents have dementia or symptoms that are reflective of dementia.

Parent Organisation

Senior managers are responsible for supporting the management team. The parent organisation is a private for-profit organisation and all residents are currently privately funded. The parent organisation allows the service to self-manage with devolved responsibility which works really well in this service.

Family involvement

Families are encouraged to be involved in any or all aspects of care and support to the degree that they choose They support life story work and bring in pictures and objects for the memory boxes outside each person’s room.

Daily routine

Morning – people rise whenever they please mostly between 7 and 10.30am. They can choose when they have breakfast which can be prepared on each unit. They can eat in their room or in the dining room or lounge. Cooked breakfast is only available from the central kitchen and so is only cooked at around 8am.

Morning activities - 10am-11am individual gym sessions with a qualified instructor, each lasting around 10-15 minutes. 11.30 am a range of activities (for example, darts, singing, volleyball) in a range of locations around the home, garden and trips out at least three times each week. Some people were already asking to use the gym when I visited, and the relevant activity co-ordinator was collecting people to work with in there.

Lunchtime – Lunch served at 12.30 pm. Three courses available, with choice for each course. Individual requests are also catered for (such as, chips, salad, sandwiches).

Afternoon activities – as morning activities

Teatime – A hot meal or sandwiches, cake, crisps and a choice of yogurts or warm pudding.

Evening activities – The activities are being extended to include a full evening activities programme, (external organisations such as the local fire service come in for bowling, there are also movie nights, entertainers and sing along). The coffee bar is also open late into the evening and there is a pub night once a fortnight with drinks and dancing.

Bedtime – people choose when to go to bed and this appears to be anything from about 7pm to 11pm although most people are in bed before 10pm. One gentleman told me that he regularly goes to bed around 2 am. As this is a high needs nursing home some people are nursed in bed 24 hours a day.

Snacks and ad hoc activities are available throughout the day. Hairdressers are onsite on Tuesdays and Thursdays and the waiting area outside the salon is used as a waiting area and people gather there to chat on those days.

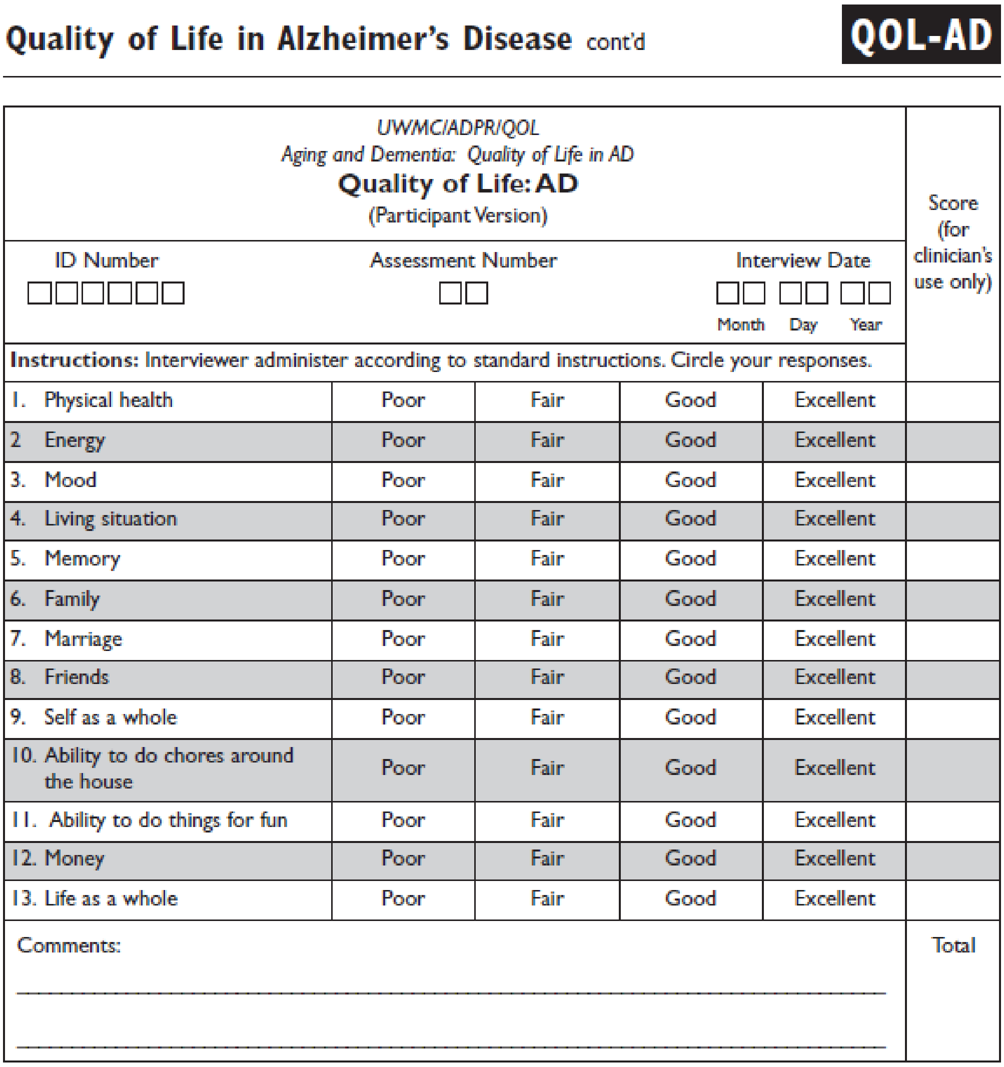
What I noticed

The first thing that I noticed was the choice of language the clinical lead used when talking about people living with dementia – she used the word ‘exploring’ where many people would use the word ‘wandering’. She also said that whilst risk assessment and management are important, living is more important! They have a very facilitative style that is not overly risk averse. The clinical lead is very proud of her team and the care that the home offers. She knew every resident by name and all of their relatives too. There were a huge number of visitors here too.

The environment is plush and beautiful, but it also felt very enabling, with people walking around and chatting in corridors. A visitor had brought a friend’s dog to visit on a dementia care unit and many of the people on the unit were stopping in the corridor to stroke it and chat. I asked a gentleman in a wheelchair with limited language if he liked the dog and he smiled. I encouraged him to stroke it and he did. I asked him if he used to have a dog and he said ‘yes a Sealyham terrier’. He appeared to be pleased and shocked that he had either remembered the name of the breed or managed to say it. As we left the unit a gentleman was standing at the door wanting to go to the gym. The clinical lead asked if he would like to walk with us as there was no-one in the gym yet, he said he would like to. He appeared to be on the brink of agitation. She diffused this with calm touch and gestures and he walked on with us for a while until a carer came to get him changed for the gym.

Appendix 8 – Quality of life in Alzheimer's disease score sheet

Quality of life in Alzheimer's disease participants score sheet (Logsdon et al., 1999)



Quality of Life in Alzheimer's Disease cont'd **QOL-AD**

UWMC/ADPR/QOL
Aging and Dementia: Quality of Life in AD
Quality of Life: AD
(Participant Version)

ID Number ☐☐☐☐☐☐

Assessment Number ☐☐

Interview Date ☐☐ ☐☐ ☐☐
Month Day Year

Score (for clinician's use only)

Instructions: Interviewer administer according to standard instructions. Circle your responses.

					Score (for clinician's use only)
1. Physical health	Poor	Fair	Good	Excellent	
2 Energy	Poor	Fair	Good	Excellent	
3. Mood	Poor	Fair	Good	Excellent	
4. Living situation	Poor	Fair	Good	Excellent	
5. Memory	Poor	Fair	Good	Excellent	
6. Family	Poor	Fair	Good	Excellent	
7. Marriage	Poor	Fair	Good	Excellent	
8. Friends	Poor	Fair	Good	Excellent	
9. Self as a whole	Poor	Fair	Good	Excellent	
10. Ability to do chores around the house	Poor	Fair	Good	Excellent	
11. Ability to do things for fun	Poor	Fair	Good	Excellent	
12. Money	Poor	Fair	Good	Excellent	
13. Life as a whole	Poor	Fair	Good	Excellent	

Comments: ______________________________

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Total