Exploring homecare for people living with dementia using an ethnographic approach

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Declaration

I, Monica Leverton, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Funding

Acknowledgements

Todd, my appreciation to you stems back to helping me make the decision to embark on this PhD journey. You kept your promise of helping me to find a balance between keeping my head down and continuing to make sure our lives were exciting. Thank you for always being on hand to help me use Excel or format a table… but you still can't be a co-author.

This work is dedicated to my Nana, who was and will continue to be my main source of inspiration. I am indebted to her for her unconditional love and pride, for teaching me empathy and instilling my compassion for others, and for encouraging me to believe I could achieve anything I put my mind to.

Abstract

Background

Most people living with dementia prefer to remain in their own homes. Support from homecare services can enable this, yet homecare workers often receive limited training and support.

Aim

To learn and understand from the experiences of homecare workers how they can be better trained and supported in their role, and how they can support independence in people living with dementia.

Methods

I conducted a systematic review of observation methods used to study homecare. This informed the design of my ethnographic study, comprising participant observations with 16 homecare workers and 17 clients living with dementia, and 82 qualitative interviews with people living with dementia, family carers, homecare staff and health and social care professionals. I triangulated the data and thematically analysed the findings. I used my findings to inform the coproduced NIDUS-Professional training and support intervention.

Findings

The value of homecare relationships and the significance of the home were two prominent, overarching findings. Relationships between homecare workers, clients, family carers and other health and social care professionals were often complex to navigate, yet were key to meeting the needs of people living with dementia. Care provision in the home setting transitioned the environment into a hybrid space between the clients' domestic space and the homecare workers' workplace.

Conclusion

In highlighting the significance of the home for people living with dementia, I posit the importance of responsive, person-centred and home-centred care. Relational and emotional aspects of homecare are central to workers' training and support. Establishing interdependent, collaborative relationships with clients can enable meaningful decision-making and active participation in daily tasks. Recognising and valuing homecare workers' position amongst multidisciplinary dementia-care services, alongside managerial and peer support, may reduce some of the role's associated challenges. Moving towards professionalisation of the homecare workforce is a clear direction for future research, policy and practice.

Impact statement

My research investigated how people living with dementia can be supported to live with independence, through better training and support of the homecare workforce. This is a national policy priority (Department of Health, 2015c). My study is one of the largest qualitative explorations in this area, and among the few to directly include the experiences of people living with dementia.

I reviewed methods for observing care at home, publishing this work in a review (Leverton et al., 2019), which has been cited by research informing methodology for designing age-friendly homes (Brookfield, Scott, Tinker, & Ward Thompson, 2020). I presented my findings at King's College London's (KCL) Home Care Research Forum (February 2019) to an audience of academics and staff from local authorities, charities and homecare organisations. This work supported the development of my study methodology and sparked my interest in ethnographic methods. I have led UCL Qualitative Research Working Group workshops on topics including ethnography, visual methods and meaningful qualitative analysis. I delivered two presentations at UCL's Qualitative Health Research Network Conferences: 'Crafting the Future of Qualitative Health Research in a Changing World' (March 2019) and 'Truth, Trust and Research in Health and Social Care' (September 2020). I delivered UCL MRes lectures on 'Independence at Home for People Living with Dementia', based on my ethnographic work (in 2019 and 2020).

I have engaged with academic and non-academic audiences nationally and internationally. I was invited to talk at the SAFE (Safer Living for Older Women) conference in Bucharest, Romania (October 2019), to professionals and policy makers. In November 2019, I co-delivered a workshop at the Tokyo Metropolitan Institute of Medical Science, Japan, on the NIDUS study and my PhD work. I presented my findings at the virtual Alzheimer's Disease International Conference, Singapore (December 2020). In terms of UK impact, I was invited to present my work at the ADNE (Association of District Nurse & Community Nurse Educators) conference, Nottingham (November 2019), returned to KCL's Home Care Research Forum to

provide an update on my research (February 2020) and spoke at the annual Age UK conference on Older People's Health & Social Care (March 2021).

I have participated in several public engagement events. I was awarded a UCL bursary to attend the Cheltenham Science Festival (June 2019) to explore ways of engaging the public in research. At the 'It's All Academic Festival' (October 2019), I used a doll's house, together with my photographs and sketches, to communicate the concept of independence to children and young adults. In September 2020, I joined 55 researchers in a live charity event ('Dementia Chatathon') for Alzheimer's Research UK, discussing my findings.

My findings have directly informed the development of the NIDUS-Professional training intervention (discussed in Chapter 9). In addition to my three first author publications that report my PhD findings, I have contributed to five further NIDUS publications (Herat-Gunaratne et al., 2020; Lord et al., 2020; Rapaport et al., 2020a; Rapaport et al., 2020b; Rees et al., 2020).

(Image blurred for confidentiality – photos from presentations in the UK, Romania and Japan)

Conjoint statement

My PhD research was carried out as part of the New Interventions for Independence in Dementia (NIDUS) programme [Alzheimer's Society Centre of Excellence grant 330]. My ethnographic study (presented in Chapter 4), involving qualitative interviews and participant observations, informed the development of the coproduced NIDUS-Professional training and support intervention for homecare workers who provide care to people living with dementia. I was part of a research team that collected this data.

Eighty-two qualitative interviews were completed; I undertook 25 interviews (30.5%); the remainder were completed by Alexandra Burton (25 interviews), Jules Beresford-Dent (20 interviews), Ruminda Herat Gunaratne (10 interviews) and Penny Rapaport (2 interviews). Across all participant groups, I carried out just over half (53.3%) of the interviews with homecare staff (16/30), nearly a quarter (18.2%) of interviews with people living with dementia (2/11), a sixth (13.6%) of interviews with family carers (3/22), and a quarter (21.1%) of interviews with health and social care professionals (4/19).

The participant observation design was informed by my systematic review of observational methods of adult homecare. Alexandra Burton assisted with screening the papers, and Jessica Rees and Claudia Cooper provided support with assessing the quality of the included papers. The participant observations were conducted as a team-based ethnography by three researcher-observers: Alexandra Burton, Jules-Beresford Dent and myself, who were each responsible for observations in two of the six participating homecare agencies. I led the methodological planning and oversaw this aspect of the study. Of the 104 participant observations, I carried out 57 observation visits (54.8%), Alexandra observed 23 visits and Jules observed 24 visits. I led weekly discussions between the researcher-observers, a reflective practice session in November 2018 and an initial analysis session of the observation fieldnotes with the wider NIDUS team in February 2019.

In Chapter 8, I describe how my findings informed the NIDUS-Professional training and support intervention. This intervention was coproduced by the whole research

team, including the NIDUS PPI (patient and public involvement) group. I led the integration of findings from the work described above, into the intervention. I presented findings to the coproduction group, participated in the workshops, and distilled the many pages of transcripts, photographs and sketches from my ethnographic work to provide suggested material, from which the coproduction group selected quotes and observations to include in the training.

Thus, where I use the term 'we' in this thesis, I refer to the research team listed above.

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Monica Leverton

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Professor Claudia Cooper

Abbreviations

AB	Alexandra Burton
ADLs	Activities of Daily Living
BAME	Black, Asian and Minority Ethnic
BOUGH	Broadening Our Understanding of Good Homecare
CC	Claudia Cooper
CQC	Care Quality Commission
FC	Family Carer
HM	Hassan Mansour
HRA	Health Research Authority
HSCP	Health and Social Care Professional
HCW	Homecare Worker
HCM	Homecare Manager
IA	Ignacia Azocar
JBD	Jules Beresford-Dent
JM	Jill Manthorpe
JR	Jessica Rees
LPA	Lasting Power of Attorney
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIDUS	New Interventions for Independence in Dementia

NVQ	National Vocational Qualification
PITCH	Promoting Independence Through Quality Dementia Care at Home
PLwD	Person Living with Dementia
PPE	Personal Protective Equipment
PPI	Patient and Public Involvement
PR	Penny Rapaport
PRIDE	Promoting Independence in Dementia
RCT	Randomised Controlled Trial
RHG	Ruminda Herat Gunaratne
SGC	Stefanny Guerra Ceballos
UKHCA	United Kingdom Home Care Association
WHELD	Improving Wellbeing and Health for People with Dementia

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Chapter 1   Introduction

My interest in dementia came from personal experience of caring for my grandmother who was diagnosed with Alzheimer's disease at the age of 90. As a family, we were able to support her to remain living in her own home, with the support of homecare workers. Seeing the positive impact of enabling my grandmother to stay in the home she had lived in for several decades inspired me to apply for an Alzheimer's Society funded PhD at UCL.

1.1   Research outline

My research is nested within a wider study programme: New Interventions for Independence in Dementia (NIDUS) [Alzheimer's Society Centre of Excellence grant 330]. The NIDUS study is a five-year research programme, which began in March 2018. It consists of two streams of work, aiming to support independence at home for people living with dementia, their family carers (NIDUS-Family) and homecare workers (NIDUS-Professional). My PhD is embedded within the stream of work that has informed the development of NIDUS-Professional; a coproduced training and support intervention for homecare workers who support people living with dementia.

In my research I have taken a qualitative ethnographic approach. First, I reviewed the literature regarding methods employed in observational studies of care provided in the home setting (Chapter 3). This informed the design of my participant observations, which formed part of my team-based ethnographic study of homecare for people living with dementia, alongside qualitative interviews (Chapter 4). This work built upon the outline originally developed in the NIDUS grant application by the study investigators, who include my three supervisors. I worked within a research team carrying out qualitative interviews with a range of stakeholders in dementia care and conducting observations of homecare delivery to people living with dementia. In writing this thesis, I triangulated these interview and observation findings to gain a richer 'on the ground' understanding of homecare for people living with dementia. I was also part of the team coproducing the NIDUS-Professional

training intervention for homecare workers that my PhD studies informed. I report on the coproduction process, and how I was involved in it, in this thesis. The methodological process of my PhD is illustrated in Figure 1.1.
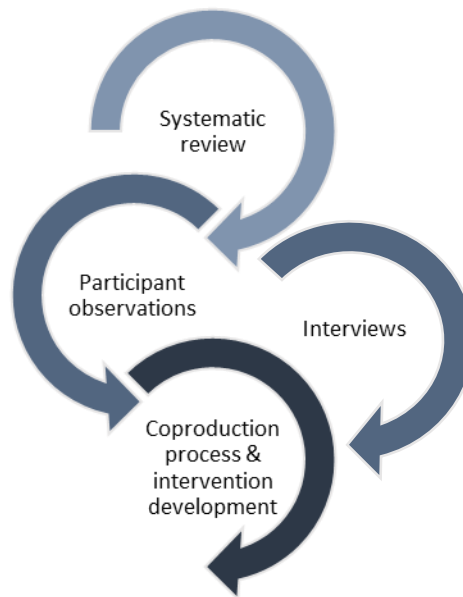
Figure 1.1: The methodological process of my PhD

In this chapter, I present an overview of the literature to contextualise my research. I will begin by introducing the topic of dementia: its definition, prevalence and symptoms. I then consider the needs of people living with dementia in line with existing frameworks, and outline how social care provision can be implemented to meet these needs. I will describe the homecare sector and workforce, models of care and existing staff training interventions, and then introduce the key theoretical frameworks that are pertinent throughout my research. I end this chapter by situating ethnography as my chosen methodological design, within the context of research with people living with dementia.

1.2 Background

1.2.1 Dementia

1.2.1.1 Definition

Dementia is defined in the International Classification of Diseases-11th Revision (ICD-11) as 'an acquired brain syndrome characterised by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgment, psychomotor speed, visuo-perceptual or visuo-spatial abilities). The cognitive impairment is not entirely attributable to normal aging and significantly interferes with independence in the person's performance of activities of daily living' (World Health Organisation, 2018). Thus, the loss of some degree of independence is a central tenet of a dementia diagnosis. Dementia is used as an umbrella term for many different forms of the syndrome; the most prevalent being Alzheimer's disease (60-70% of cases globally), followed by vascular dementia, with other forms including dementia with Lewy bodies, frontotemporal dementia, Parkinson's dementia, and mixed dementia (World Health Organisation, 2020).

1.2.1.2 Epidemiology

Globally, dementia is a leading cause of disability (World Health Organisation, 2017a, 2020). It affects over 46 million people; and this is expected to rise to 131.5 million by 2050 (Prince et al., 2015). The majority of people living with dementia are women (65%) (Prince et al., 2014), and aged over 65 years (Matthews et al., 2013). With an ageing population worldwide, the overall prevalence of dementia is rising; although age-specific prevalence of dementia is declining in many parts of the world, probably due to improvements in lifestyle and education (Livingston et al., 2020). Data collected in the UK found a higher incidence of dementia diagnoses in people living with dementia in Black ethnic communities, while those from Asian ethnic groups had lower incidence rates than people from White ethnic groups (Pham et al., 2018). Similar results have been found globally (Mayeda, Glymour, Quesenberry, & Whitmer, 2016; Mehta & Yeo, 2017), and are likely to reflect variation in receipt of

timely diagnosis (with minority ethnic communities less likely to receive this) and different underlying risks of dementia (Roche, Higgs, Aworinde, & Cooper, 2020).

1.2.1.3 The course of dementia illness and prognosis

As the average age of the population continues to rise, dementia remains a national and global health challenge, with profound impacts on those living with dementia, their family members and carers, in addition to the wider society and economy (Prince et al., 2015). Dementia is becoming one of the leading causes of death (Etkind et al., 2017), and an illness that one in three people over the age of 65 in the UK are estimated to die from (Brayne, Gao, Dewey, & Matthews, 2006). Living with dementia has an estimated life expectancy of 6.9 to 10.7 years in those diagnosed at age 65-69, and 1.9 to 3.8 years when diagnosed at age 90 and over (Rait et al., 2010; Xie, Brayne, & Matthews, 2008).

Dementia is an illness that progresses through stages delineated as mild, moderate and severe. The rate of progression varies widely, and stages of dementia may overlap, with symptoms appearing earlier or later than outlined by the Clinical Dementia Rating Scale. Thus, the symptoms of dementia affect each individual differently. To quote Tom Kitwood, 'if you've met one person with dementia, you've met one person with dementia' (Kitwood, 1997b).

It is estimated that just under 40% of older people living with dementia in England reside in care homes, while around 60% remain living in the community (Wittenberg et al., 2019). Although the majority of people living with dementia prefer to remain living in their own homes, a move to a residential care setting is often necessitated by a breakdown in family care, where family carers no longer feel able to care for their relative at home (Cole, Samsi, & Manthorpe, 2018; Samsi, Cole, & Manthorpe, 2019); particularly where perceived risks outweighed the benefits of living at home (Lord, Livingston, Robertson, & Cooper, 2016). With the increasing incidence of dementia, there will continue to be greater demand for both formal and informal support to enable people living with dementia to remain living at home.

1.2.2 Needs of people living with dementia

Dementia is a main cause of disability later in life. People living with dementia have complex needs and experience greater loss of daily functioning, resulting from behavioural, psychological, and cognitive symptoms of the disease, as well as physical comorbidities.

1.2.2.1 Behavioural and psychological symptoms of dementia

People living with dementia are often at increased risk of developing behavioural and psychological symptoms, including anxiety, depression, apathy, disinhibition, sleep disturbances, aggression and agitation, relative to people without dementia. Behavioural symptoms can have a profound impact on daily functioning, while psychological symptoms can greatly reduce motivation to initiate and partake in daily activities and connect with the people around them (Saari, Hallikainen, Hintsa, & Koivisto, 2020). Behavioural and psychological symptoms can be the most complex and stressful aspects of dementia for the individual, their family members and care providers (Kales, 2015).

Symptoms that present as behavioural disturbances are often termed 'challenging behaviours' or 'behaviours that challenge'. However, this medicalised approach to understanding behaviour is debated; Wolverson et al. (2019) for example, argues that these behaviours can be understood as distressing behaviours or expressions of unmet need in people living with dementia. Such behaviours can be framed within the Needs Driven Dementia-Compromised Behaviour (NBD) model, that positions behaviours that challenge as attempts by people living with dementia to accomplish goals or express needs (Algase, 1996). Need-driven behaviours can include restlessness, repetitive questioning, aggression and resistance to care, that can be caused by a combination of individual characteristics/background factors and proximal factors (i.e. social or environmental triggers) (Norton, Allen, Lynn Snow, Michael Hardin, & Burgio, 2010). With this view, it is possible to understand and respond to behaviours that challenge to improve quality of life for people living with dementia, and those involved in their care.

For consistency, I will use the term 'behaviours that challenge' to describe distressing behaviours in this thesis.

1.2.2.2 Cognitive and functional impairments

Daily functioning can be operationalised as an individual's ability to carry out activities of daily living (ADLs). Cognitive impairments such as orientation and memory loss can affect an individual's daily functioning, including the ability to attend to ADLs such as personal care, dressing, eating and drinking, managing medication and comorbid physical health conditions, as well as the ability to drive and access the community (Mograbi et al., 2018). Giebel and colleagues (2015) found that functional ability to carry out ADLs such as bathing, dressing and continence began to decline from the early stages of dementia, while 'toileting' and 'feeding' become more challenging in the moderate to severe stages of dementia.

1.2.2.3 Physical comorbidity

Most people living with dementia have multiple comorbid or concurrent health care needs. A retrospective cohort study over 5-years identified that the vast majority (91.7%) of 4,999 participants diagnosed with dementia had one or more additional comorbidity or long-term health conditions (Browne, Edwards, Rhodes, Brimicombe, & Payne, 2017). Dementia can make it difficult for individuals to manage their physical health (Bunn et al., 2014; Rees et al., 2020). Emergency hospital admissions are also high in people living with dementia; this could be reduced through improved access to high quality primary care and health care management, and to social care (Kasteridis et al., 2015).

1.2.2.4 Needs of people living alone with dementia

An estimated 120,000 people in the UK are living alone with dementia (Alzheimer's Society, 2019). People living alone with dementia are at greater risk of unmet social, psychological, medical and environmental needs (Miranda-Castillo, Woods, & Orrell, 2010). In a recent UK study looking at data from 1,541 people living with mild to moderate dementia, loneliness, lower life satisfaction and greater use of homecare services were more frequently reported by those living alone (Clare et al., 2020). It can be difficult for people living alone with dementia to access information and

coordinate relevant support services (Alzheimer's Society, 2014). As such, it is important for provisions to be in place to both identify these vulnerable individuals, and for services to provide a higher level of support and regular monitoring of their wellbeing (Miranda-Castillo et al., 2010).

Encouraging people living alone with dementia to accept support can be challenging. Remaining independent for people living alone with dementia is important, and for some, the use of support services such as homecare is a sign of losing their independence (Durand, James, Ravishankar, Bamrah, & Purandare, 2009). Qualitative research by Toot and colleagues (Toot et al., 2013; Toot, Swinson, Devine, Challis, & Orrell, 2017) highlighted an association between individuals rejecting community support services, and crisis admissions to either hospital or care home placement.

1.2.3 Meeting the needs of people living with dementia

With the progressive loss of daily functioning, many people living with dementia will need support from family carers and/or paid care services to maintain independence and function in daily life. To understand how the needs of people living with dementia can be met, I considered Maslow's hierarchy of needs (Maslow, 1943), in addition to theories of personhood, person-centred care, relationship-focused care and the concepts of independence and active ageing.

Maslow depicted human needs as hierarchical, whereby lower levels represent the most fundamental, physiological levels of need such as feeling comfortable, free from pain, safe and secure (Maslow, 1943). Higher levels of need reflect belongingness and self-esteem, achieved by having relationships and feeling loved and respected. The highest levels of need, self-actualisation and transcendence can be met through opportunities for personal fulfilment. The premise of Maslow's theory is that for higher levels of need to be met, the fundamental human needs must first be fulfilled, whilst unmet needs subsequently result in physical and/or psychological distress (Maslow, 1943). This can present as behaviours that challenge in people who are unable to communicate unmet need or distress.

In the context of people living with dementia, Maslow's theory can be used as a framework to assess quality of life through met and unmet needs. Observing people living with dementia admitted to acute medical wards, Scerri (2020) found that basic fundamental needs such as toileting, feeding, drinking and comfort were not always met by care staff, particularly with individuals who were unable to communicate, resulting in patients feeling devalued and isolated. Across residential settings, safety needs are typically prioritised over higher-level needs such as social contact, dignity and respect (Buron, 2008; Scerri et al., 2020). The importance of meeting the emotional and relational needs of people living with dementia has been encouraged in hospital, care home and homecare settings (Bailey, Scales, Lloyd, Schneider, & Jones, 2015; Pollock, Wilkinson, Perry-Young, & Schneider, 2020; Schneider et al., 2019; Turner et al., 2018); albeit less focus has been given to homecare provision for people living with dementia.

1.2.3.1 Personhood and person-centred care

Much of Maslow's work is reflected in Tom Kitwood's theories of personhood and person-centred care (Kitwood, 1997b; Kitwood & Bredin, 1992). The fundamental principles of Kitwood's work reject the traditional biomedical model of dementia care, instead positing a relational approach situating the individual within their social context. Applied to homecare, this acknowledges the importance of the client's social network in supporting the individual. At the core of Kitwood's theory, the concept of personhood relates to the attributes of an individual that make them a person (i.e. their personality, interests, beliefs, values, likes and dislikes) (Kitwood, 1997a; Kitwood & Bredin, 1992). According to Kitwood, personhood is something that is granted by others and thus 'one can be a human being, and yet not be acknowledged as a person' (Kitwood, 1997a).

There is some debate around the extent to which the attributes of individual personhood, such as self-awareness, affect, moral agency, cognitive functioning and the ability to communicate deteriorate as dementia progresses, and how much they are concealed by the nature of traditional models of dementia care that prioritise task-orientated over relationship-focused approaches (Buron, 2008). Pertaining to the latter, this argument suggests that without a focus on meaningful relationships

and interactions for people living with dementia, personhood becomes lost and symptoms of dementia are exacerbated.

Person-centred care can be considered the process by which personhood is maintained (Manthorpe & Samsi, 2016). The philosophy of person-centred care moves away from an approach that prioritises organisational processes and schedules, rather placing the individual at the centre of their care, and focuses on the relational and interactional underpinnings associated with wellbeing, quality of life and personhood (Kitwood, 1998).

As such, Kitwood's theory states that personhood and person-centred care can be upheld for all individuals living with dementia, regardless of impairment (1997a). In this sense, if the person living with dementia has impaired communication, family members can provide opportunities for others, such as homecare staff, to learn about the individual's past and present life – the defining attributes that make them a person. Homecare staff trained to deliver person-centred dementia care were found to have improved attitudes towards people living with dementia, particularly around providing dignified and respectful care (Kingston, 2008). Relationships and social networks are therefore key to maintaining personhood in people living with dementia (Smebye & Kirkevold, 2013). This is particularly pertinent in understanding how to meet their holistic needs; from the fundamental human needs to the higher-level needs as conceptualised by Maslow (1943).

Acknowledging personhood and providing person-centred care are increasingly considered the gold-standard in policy and practice for supporting people living with dementia (NICE, 2011). Yet, Kitwood's work is not unanimously accepted by all. Critics argue that the concept of personhood depends on individuals possessing autonomy, agency, consciousness and memory; thus rejecting the reality of living with dementia (Dewing, 2008a; Higgs & Gilleard, 2016). Likewise, the premise of person-centred care places the person at the centre of their care decisions, however, as argued by Higgs and Gilleard (2016), the responsibility of achieving and maintaining personhood and person-centredness in people living with dementia falls on others. This debate is part of the premise for the authors' discussion of a

Fourth Age paradigm, whereby individuals are depicted as 'ageing without agency', lacking capacity to express full personhood (Higgs & Gilleard, 2015); individuals said to be in the fourth age depend upon others to uphold their agency.

1.2.3.2 Relationship-focused care

Relationship-focused care theories (also termed relationship-centred care) expand upon a person-centred care approach, whereby care is not only about the individual being at the centre, but their interconnected social network too (Hebblethwaite, 2013). This idea of social connectedness extends to varying levels of social relationships, including family, friends, professionals and the wider community (Nolan, Davies, Brown, Keady, & Nolan, 2004).

Relationship-focused care therefore moves beyond the individual, to acknowledge the significance of partnership and the mutual and reciprocal nature of such relationships. The needs of family members and care professionals are also valued and recognised within this framework (Hebblethwaite, 2013). Good relationships between homecare workers and people living with dementia have been shown to be mutually beneficial and enjoyed, with homecare staff reporting close relationships with clients as a primary benefit of their job (Ben-Arie & Lecovich, 2014; Butler, 2009; D'Astous, Abrams, Vandrevala, Samsi, & Manthorpe, 2017). This approach therefore aligns closely with Kitwood's work, whereby personhood, according to Kitwood, is socially constructed, thus a relationship-focused approach can promote and sustain personhood in people living with dementia, and improve job satisfaction for homecare workers.

Work by Kadri et al. (2018) considered the personhood of care home staff supporting people living with dementia. They found that care workers were not valued as individuals in their own right by their employer, but rather as instruments in which to facilitate person-centred care. Such practices undermine the morality of the work and complexity of relationships involved in delivering care. Acknowledging the needs of the person living with dementia, as well as their social network is a way of transitioning the concept of person-centred care 'to be a philosophy that includes all those who work in dementia care' (Kadri et al., 2018).

1.2.3.3 Independence, ageing and dementia

Independence as a concept has been defined as 'the ability to function in daily life with no or little help from others' (World Health Organisation, 2002). It is operationalised as the ability to be autonomous, to make decisions and perform ADLs without assistance (Guess, Paul, & Lane, 2011). The challenges associated with both ageing and dementia confront this notion of independence. As such, the fourth age paradigm and relationship-focused care theories (described above) are closely connected with debates around independence, ageing and dementia, particularly in their application to homecare.

With increased susceptibility to disease, disability, and declining cognition, a person's ability to function independently and perform ADLs without assistance usually declines with age (Sander et al., 2014). Loss of functional independence and therefore, increased dependency, can negatively impact self-worth and dignity, while retaining independence and meaningful participation in activities are associated with increased quality of life and satisfaction for people living with dementia (Levasseur, Desrosiers, & Tribble, 2008; Van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2014). People living with dementia have conceptualised good quality of life as being able to make decisions and choices, maintaining independence, being respected and treated as an equal in their care and continuing with their daily and family life (Dementia Action Alliance, 2017; Kelly & Innes, 2016; Lord et al., 2020; Rapaport et al., 2020a; Yates et al., 2019).

The National Institute for Health and Care Excellence (NICE) reframed the concept of independence as 'the ability to make choices and to exercise control over your life. This includes being able to live independently with or without support' (2015b, p. 40). There has been a paradigm shift towards the notions of 'active ageing', 'positive ageing' and 'healthy ageing', as 'the process of developing and maintaining the functional ability that enables wellbeing in older age'; focusing on providing individuals with the capabilities to function by drawing upon home, community and broader societal support (World Health Organisation, 2015).

The World Report on Ageing and Health (World Health Organisation, 2015) called for comprehensive public health action to change how ageing is perceived and responded to, for worldwide social and economic benefits in terms of the health, wellbeing and societal participation of older people. Yet while this may be a welcome change for some, this promotion of active and positive ageing may, paradoxically, lead to societal marginalisation and repression of ageing (Raymond, 2019; Tulle-Winton, 1999), diminishing the experiences and reality of old age including ill-health, functional decline and dependency (Boudiny & Mortelmans, 2011; Van Dyk, 2014). This echoes the debate presented above, relating to theories of personhood in dementia.

Independence for people living with dementia may therefore be more usefully conceptualised as the ability to manage life with 'some degree of independence' (Dröes et al., 2017; Martin, Turner, Wallace, & Bradbury, 2013), including the ability to live at home for as long as possible (Rowland, 2012). As many people living with dementia are supported to live at home by family members, friends, neighbours and paid support services, recent models of dementia care highlight a tension between independence and the interdependence that can enable people living with dementia to remain at home for as long as possible (Lord et al., 2020). Interdependence as a concept recognises the interconnectedness that shapes people's lives, much like the premise of relationship-focused care theory presented above (Behuniak, 2010; Nolan et al., 2004).

1.2.3.3.1 *Interventions promoting independence in dementia*

A number of interventions have sought to promote independence in dementia (Steinberg, Leoutsakos, Podewils, & Lyketsos, 2009; Teri et al., 2003), yet few have included people living with dementia in their conception. Both the Promoting Independence in Dementia (PRIDE) programme (Csipke et al., 2018; Yates et al., 2019) and the NIDUS programme (which my PhD is embedded within) (Rapaport et al., 2020b), are interventions that have been coproduced with people living with dementia, that aimed to promote independence.

The PRIDE programme (Csipke et al., 2018) focused on promoting independence in people living with mild dementia in the community, by enabling them to participate in activities that developed their communication and decision-making skills. The intervention was received positively overall and reportedly helped to instil hope and confidence in people living with mild dementia, as well as reducing fear following their initial dementia diagnosis (Csipke et al., 2020). The authors concluded that for a future randomised controlled trial (RCT) of the PRIDE intervention, these findings suggest targeting self-management skills and perceived confidence in employing these skills, as the primary outcomes (Csipke et al., 2020).

The NIDUS programme aims to help both family carers and care professionals in supporting people with dementia to live at home as independently as possible (Lord et al., 2020; Rapaport et al., 2020b). My PhD informed the NIDUS-Professional intervention focusing on homecare workers. The NIDUS-Family intervention aims to support family carer and person living with dementia dyads, through an evidence-based goal-focused manualised programme (Rapaport et al., 2020b). The intervention seeks to help participant dyads to identify and prioritise their needs and goals, to use strategies to reduce disabilities associated with functional and behavioural impairments, and to enable self-management. A pilot study of the NIDUS-Family intervention found it to be feasible and acceptable to participants (Rapaport et al., 2020b). A RCT to evaluate its effectiveness in supporting goal attainment in the care of people living with dementia is currently underway.

1.2.4 Care and support for people living with dementia

In this section, I will begin by outlining current policies on dementia care in England. I will then explore how people living with dementia can be supported by social care services to live as well as possible in the community.

1.2.4.1 English Dementia Policy

In 2009, the Government published a national 'Living well with dementia' strategy for England, envisioning better awareness of dementia and an overall transformation of services to deliver high quality care for everyone living with dementia (Department of Health, 2009). In 2013, the first G8 dementia summit was held in London (Global

Action against Dementia, 2013). It set out a strategy for greater investment and innovation to improve prevention and treatment of dementia, and to improve the overall quality of life for people living with dementia by 2025. In 2015, the Prime Minister's Challenge on Dementia 2020 emphasised the 'catastrophic' impact of dementia and outlined a national plan to improve dementia care through greater funding, research, understanding and compassion (Department of Health, 2015b). This report outlined policy aspirations to enable more people with dementia to live at home independently for longer through greater provision of high-quality homecare, including personalised care specific to the individual, their relatives and carers, and greater recognition of homecare services by health and social care commissioners.

However, health and social care services for people living with dementia are fragmented and their expenditure varies considerably (Peel & Harding, 2014; Wittenberg et al., 2019). In England, the cost to the public in terms of National Health Service (NHS) care and treatment for people living with dementia (£4.9 billion) is considerably smaller than the cost of social care to the public (£11.2 billion), however over half of social care costs are paid by the person living with dementia and their family members (Wittenberg et al., 2019). The potential for more coordinated and integrated dementia care services to improve quality of care for people living with dementia and their family carers has been widely debated (National Collaborating Centre for Mental Health, 2007). The NHS Long Term Plan (NHS England, 2019) outlines the need for people to have more choice and control in their care through a personalised care approach. While this plan is not dementia-specific, it is listed as a condition, amongst others, that identifies individuals with greater risks and needs, who should be offered personalised care to support 'both their physical and mental health needs', to enable them to maintain their independence (NHS England, 2019, p. 17).

1.2.4.2   Social care support

There is a range of post-diagnostic health and social care support services for people living with dementia. Both pharmacological (i.e. cholinesterase inhibitors) and non-pharmacological interventions (i.e. cognitive stimulation therapy) can help

to reduce the severity of behavioural, psychological, cognitive and physical symptoms of dementia. Social care can support people living with dementia to live well and with independence, in their own homes, day centres and residential facilities. In England, 90,000 older people living with dementia in the community are estimated to be in receipt of paid social care support, including support workers and homecare services (22%), while the majority receive informal unpaid care, usually provided by a family carer (65%) (Wittenberg et al., 2019); some people receive both unpaid and formal support.

Social support can include personal care and assistance with daily tasks, reablement, providing advice and signposting for both the care recipient and their family carers, as well as advising on and providing aids and adaptations in the home (The King's Fund, 2019). Social care services and social workers have a central role in assessing individual need, translating this into the client's care plan or 'package', and setting up and monitoring the necessary resources and sources of support (Department of Health, 2015a). They liaise across services and with the individual, family carers and professionals delivering the care to clients.

Social care in England is a responsibility of local authorities under the Care Act 2014 and is means tested and needs assessed. A third of people living with dementia in England receive local authority funded support (Alzheimer's Society, 2020), where the local authority contributes to or pays for the cost of social care (Age UK, 2020). Those who are not eligible can only receive social care if they pay privately (The King's Fund, 2020a). This is one of the reasons why, overall, the majority of social care in England is provided by unpaid family carers.

1.2.4.2.1 Informal or family carers

Informal or unpaid family carers supporting individuals living with dementia are estimated to 'save' the UK economy £13.9 billion per year (Alzheimer's Society, 2021). In 2014, 700,000 family and friend carers provided support for someone living with dementia in the UK (Giebel et al., 2015; Giebel et al., 2014; Lewis, Karlsberg Schaffer, Sussex, O'Neill, & Cockcroft, 2014). Family members typically become carers for relatives living with dementia, through willingness or sense of duty (Camden,

Livingston, & Cooper, 2011). The negotiation of caring roles is not straightforward (Egdell, 2013) and care networks may also include several informal carers, or occasionally none – this latter group of people living with dementia relying solely on support from homecare services.

Lack of support to make decisions and navigate services and sources of care can be distressing for family carers (Lord, Livingston, & Cooper, 2015; Samsi & Manthorpe, 2013). Caring for an individual living with dementia can negatively impact on a family carer's health, wellbeing, finances, family life and employment (Cross, Garip, & Sheffield, 2018; Goren, Montgomery, Kahle-Wrobleski, Nakamura, & Ueda, 2016; Li et al., 2014); 15% of informal carers in England are unable to work because of their caring responsibilities, while 48% have a long-standing illness or disability of their own (NHS Digital, 2017). Carer stress can also impact the care recipient. Family carer depression and anxiety have been associated with abusive behaviour towards individuals living with dementia (Cooper, Blanchard, Selwood, Walker, & Livingston, 2010a; Cooper et al., 2010b). This is also associated with a greater risk of moving to a care home (Lord et al., 2016), with the belief that this may be in the person's best interests (Cole et al., 2018).

1.2.4.3   Homecare services

Homecare, also termed domiciliary care, may be part of a client's social care support package. Most people living with dementia prefer to remain in their own homes and can be supported to do so by homecare services (Lakely, Chandaria, Quince, Kane, & Saunders, 2012) that can support them with routine household tasks, personal care or respite care; excluding clinical or health care support. Homecare can help individuals maintain comfort, independence, and contact with their community (UKHCA, 2020). This support can vary from once a week, to multiple visits per day, to a live-in care package.

Varied terms for homecare workers are used globally and include domiciliary care workers, personal care aides/assistants/attendants, homecare aides/assistants, in-home assistants, personal care aides, home health aides, direct care workers, support workers (Devlin & McIlfatrick, 2009). Home health assistants are not the same as

homecare workers as their work typically involves medical or clinical care, although there is some overlap. This overlap also applies to personal assistants who provide social care support to clients at home, but are employed directly by the client, rather than being employed, managed and regulated by a homecare agency (Woolham, Norrie, Samsi, & Manthorpe, 2019). 'Homecare worker' is the term I will use throughout this thesis.

1.2.4.4 The homecare sector and workforce

The homecare workforce is in high demand, with over 670,000 people in England estimated to receive homecare every day (Cavendish, 2013; UKHCA, 2016); 60% of those recipients are people living with dementia (UKHCA, 2015).

Over 9,000 Care Quality Commission (CQC) regulated homecare providers operated across England in 2018, employing 535,000 homecare staff (43% of adult social care sector jobs) (Skills for Care, 2020b). The vast majority of homecare providers are private or third sector organisations funded by private paying clients and/or from local authorities (UKHCA, 2016); the small remainder are local authority providers.

The CQC is the independent regulator of health and adult social care in England, including homecare agencies. It carries out regular, routine inspections of services to ensure care provision is safe, caring, effective and responsive to people's needs (Care Quality Commission, 2018). Inspections provide quality ratings of 'Outstanding', 'Good', 'Requires Improvement' or 'Inadequate'. Services that require improvement will be told by CQC how to improve, while an inadequate rating will result in CQC action against the organisation. In England in 2020, the CQC rated 5% of adult social care services as outstanding, 80% as good, 15% required improvement, while 1% were rated as inadequate (Care Quality Commission, 2020).

Similar to the general adult social care workforce, homecare workers in England are predominantly female (84%), with an average age of 43 years and of British nationality (83.4%) (Skills for Care, 2019); 79% are White and 21% are from Black, Asian and Minority Ethnic (BAME) backgrounds (Skills for Care, 2019). Over half (56%) of homecare workers are employed on zero-hour contracts; the highest proportion of staff within the social care sector (Skills for Care, 2020b). This means that the

employer is not required to set any minimum number of working hours for staff. This type of contract allows for flexibility (Moriarty, Manthorpe, & Harris, 2018), however employees have no guaranteed number of hours they will work, and therefore income is unstable. In Wales, under the Regulation and Inspection of Social Care (Wales) Act 2016, employers are required to offer staff a choice of contract after three months of employment. Paying homecare workers for travel time between client visits is not commonplace (Moore & Hayes, 2017); less than 2% of care providers in England pay travel costs (UKHCA, 2012).

1.2.4.5   The role of the homecare worker

The work that homecare workers do is often based on implicit assumptions to ensure that an individual's fundamental needs are met. To meet these varied and complex physical, emotional and relational needs, homecare workers often hold different role identities, such as that of a carer, an employee, a trainer, a parent, or a friend. Work by Van Dongen (2001) depicted role variation as a coping mechanism, observing that care workers in hospitals detached themselves from the role of a carer when dealing with 'body work' and 'dirt', so they could see beyond the undesirable but necessary parts of the job, and instead focus their efforts on the patients' emotional experiences.

Variation in homecare workers' role identity has also been positioned as a compliance-gaining strategy, termed 'altercasting', said to be used by workers in perceived low-status jobs (Kendall, Scott, & Jolivette, 2019). This theorisation of role identity assumes that 'each participant actively attempts to shape the responses of the other by projecting a representation of self (an 'identity')' (Weinstein & Deutschberger, 1964, p. 454). In essence, homecare workers take on different role identities to achieve a desired response or action from their clients.

The 'employee' role has been considered as one where care workers are void of power and pulled between the demands of the care agency and the client/their family members. Homecare workers are generally employed by an agency/service provider to care for clients; the client receiving care is not the employer and the homecare worker is not their employee. In this role, tensions have been reported

regarding the moral identity of care work – forcing a task on a client because it has been instructed by the care agency (Kendall et al., 2019).

This disassociation of power may also shift the dynamic of the caring relationship to something resembling the role of a parent or a trainer. Research by Kendall and colleagues (2019) found that when homecare workers adopted the role of a trainer, they were more likely to position themselves as a professional, working collaboratively with the client to achieve goals and tasks. With the parental role, homecare workers assumed a higher degree of power to make demands that left little room for negotiation from the client. The authors found that although their actions stemmed from feelings of genuine care for the client, homecare workers seemed less comfortable adopting the parental role, elucidated by the use of a supportive 'higher authority' (i.e. the client's adult children or their care plan) (Kendall et al., 2019).

Homecare worker-as-friend is the most commonly written about role identity. The friend role is established through a reciprocal emotional connection, and an equal power balance; the client nor the care worker are the lead decision-maker. Decisions are either made collaboratively, or by a higher authoritative figure (i.e. a family carer or other care professional). Whilst this may detract from the care workers' role as a professional, this identity is thought to empower clients as an equal contributor in the relationship (Kendall et al., 2019; Spitzer & Volk, 1971).

Working in the intimate setting of the home may further alter the dynamics of the homecare role, from that of a professional or an outsider, to someone resembling a friend or a member of the family. Karner (1998) termed this the 'fictive kin' role, whereby care provided in the private sphere of the home blurs the boundaries between professional and familial caregiving. Whilst establishing a kin-like role is often viewed positively and associated with meaningful work, homecare workers have reported feeling that greater responsibility is placed on them than care professionals in other settings (Karner, 1998; Stacey, 2005; Turner et al., 2018). Below I discuss how this relates closely to theories on emotional labour.

As such, it is important that models of care, and training and support for the homecare workforce adequately reflect the varied and complex interpersonal role, and the responsibilities and power that align with each role. A training programme developed in the US sought to enhance homecare workers' proficiency in roles beyond that of solely a care aide; other roles included a communicator, a health and medication adherence monitor, a health coach, and a healthcare system navigator (Gallup, Tomasson, & Svihla, 2018). Acknowledgment of the enhanced roles involved in homecare responded to homecare workers' desire to change the outdated perception of their work as 'glorified babysitters', to that of professional care workers (Gallup et al., 2018).

1.2.5 Models of homecare

There is much variation in types of homecare services and support provision. Globally, there are four dominant models of homecare for people living with dementia: consumer-directed care, case management, integrated care and restorative care (also known as reablement) (Low & Fletcher, 2015). A consumer-directed care model aims to provide individuals with more choice and responsibility through self-management of their care budget. Case management involves an identified care manager as a single point of contact, whose role is to assess and monitor the individual's needs. Implementation trials of a case management model for people living with dementia have shown some effectiveness (i.e. reduced care home admissions) but longer-term evidence is inconclusive (Reilly et al., 2015). Integrated care models aim to facilitate greater continuity of services (i.e. between health and social care), however this type of care model has not been trialled for use in the UK. A restorative care model focuses on rehabilitation, independence and goal setting and has been associated with improved functioning and quality of life when individuals have access to intensive service use (SPRU University of York and PSSRU University of Kent, 2009); making it a more costly model of care.

In England, homecare is often commissioned to deliver large scale care at high-volume. This type of care model, sometimes termed a 'time-and-task' approach, delivers care in short time slots that focus on meeting fundamental human needs

such as personal care (NICE, 2013b), but typically neglects higher-level needs, such as those described above (see section 1.2.3). While this model is successful in achieving high-volume of care delivery, it negatively impacts care quality and client satisfaction, and has been associated with poor staff wellbeing and high turnover (Townson, 2018). It also reduces the ability to provide personalised/person-centred services, tailored around the needs of the individual.

The King's Fund explored emerging innovative models of homecare, evolving in line with public preferences for care, and calls from policy makers to enable people to remain independent and in their own homes. Nine approaches were identified, with five evaluated as being of higher quality than current models. These were autonomous team working, personalisation, integrated care, community assets/connections, family-based support/communal living (Bennett, Honeyman, & Bottery, 2018). A personalisation model was the only approach considered plausible to implement at scale, but not cost-saving. This approach aims to promote individual choice in how homecare is both commissioned and delivered (NHS England, 2021b).

Personalisation and person-centred care approaches have repeatedly been identified as important to individuals living with dementia, in addition to continuity of care, care that values and involves carers and family members (i.e. relationship-focused care models), provision of information about choices and available services, and maintaining independence, including community connections (Care Quality Commission, 2013; Healthwatch, 2017; NICE, 2016a). These preferences are incompatible with a task-and-time approach that is considered poorly suited to respond to the individual needs of people living with dementia, family carers and professionals (Rothera et al., 2008). Time and flexibility are needed to build and maintain relationships in homecare.

Autonomous team working is another innovative model of homecare that may be effective for meeting the needs of people living with dementia. The model focuses on reorganising the delivery of care to provide care workers with more autonomy and to encourage care continuity and relationship building with clients (Bennett et al., 2018). This approach is associated with improved job satisfaction for care workers

and person-centred care provision for clients. The Buurtzorg approach in the Netherlands is an example of this type of care model: staff work autonomously and creatively in small, self-managed teams, providing co-designed care that is relationship-focused rather than task-focused (Monsen & de Blok, 2013). However, implementing such an approach in the UK would require complex nationwide political and organisational reform, given the success of the model pertains largely to the integrated health and social care system in the Netherlands.

1.2.6 Challenges faced by the adult social care sector

The adult social care sector is often under scrutiny (The King's Fund, 2020b). Budget cuts to local authorities of almost 40% since 2010 have had a profound impact on the sector, including homecare for people living with dementia (Carter, 2016b). The King's Fund (2018a) identified high rates of unmet client needs, wide variation in the provision of homecare across care providers, with limited consensus on effective models of care, low pay, support and limited training for staff. Moreover, low thresholds for social care public funding meant some people paid 'catastrophic' costs for their care (The King's Fund, 2018a, p. 9). A review by the CQC also revealed similar challenges, including problematic staffing recruitment and retention, increasing needs of older people, insufficient funding for services and inflated costs for individuals paying for their care (Care Quality Commission, 2017).

1.2.6.1 Challenges in the homecare sector

Challenges specific to the homecare sector were reported by the CQC in 2013, but this review has not since been updated (Care Quality Commission, 2013). Key concerns related to insufficient information provided to clients to enable choice, a lack of continuity of care workers and failures to inform service users of visit changes. It also identified failings in supporting homecare workers and in providing staff with necessary knowledge and skills to support clients living with dementia. In addition, homecare workers received low pay and experienced high levels of stress due to having too many visits close together (a practice sometimes termed 'call cramming'), which can result in poor quality care provision (Kingsmill, 2014).

Homecare workers often stay longer with clients in their own, unpaid time (UNISON, 2013). This, together with isolated working, limited interaction with peers, and job insecurity, has resulted in annual staff turnover of around one-third in the homecare sector (Equality and Human Rights Commission, 2011; Skills for Care, 2018); and consequent lack of care continuity for clients. Recruiting, retaining and training homecare staff is a fundamental challenge for care providers, particularly in rural locations (Jefferson et al., 2018).

1.2.6.2 Challenges to homecare provision for people living with dementia

In addition to a lack of training for staff generally, it has been widely reported that homecare workers do not receive sufficient dementia-specific training, if any. The Alzheimer's Society's Fix Dementia Care survey (Carter, 2016b) highlighted that only 2% of 1,227 people affected by dementia felt homecare workers were sufficiently trained and less than half of respondents thought homecare workers understood the needs of someone living with dementia. A systematic review also identified the need for more dementia-specific and end of life training for homecare workers (D'Astous et al., 2017).

In response to these challenges, the Fix Dementia Care campaign urged the Government to equip all homecare workers for people living with dementia with the necessary training to provide good quality care (Carter, 2016b). NICE (2013a) published guidance on 'Dementia: Independence and wellbeing, Quality Standard QS30', advocating for people living with dementia to be supported to have independence and choice. Considering that homecare workers provide the majority of social care for people living with dementia at home, it is of vital importance that the workforce is skilled and experienced (Hussein & Manthorpe, 2012).

The Prime Minister's Challenge on Dementia 2020, as discussed above [see section 1.2.4.1], envisioned a rise in the number of people living with dementia being able to live at home, through 'greater provision of innovative and high-quality dementia care provided at home, suitable to the individual needs of the person with dementia, their carers and families' (Department of Health, 2015c, p. 31). In order for this to be achieved, the Government suggested that homecare needs to be viewed as an

'attractive profession'; thus, it is imperative for these challenges to be addressed and overcome.

1.2.7 Training the homecare workforce

The CQC provides guidance to all regulated homecare agencies. Regulation 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations (2014), states that staff must receive appropriate training, support and professional development to carry out duties of the role, and to be enabled to obtain further qualifications appropriate to their work. There is an expectation (not obligation) that care providers follow the standards of the Care Certificate in supporting, skilling and assessing new staff to carry out their roles.

The Care Certificate is an 'agreed set of standards for the knowledge, skills and behaviours expected of specific job roles in the health and social care sectors' and was developed by Skills for Care and Health Education England (Skills for Care, 2015). These standards are shown in Figure 1.2. The Care Certificate is available for all homecare staff but is not mandatory; although it is mandatory for new health and social care staff to receive general induction training from their employer.

The Care Certificate Standards

1. Understand your role
2. Your personal development
3. Duty of care
4. Equality and diversity
5. Work in a person-centred way
6. Communication
7. Privacy and dignity
8. Fluids and nutrition
9. Awareness of mental health, dementia and learning disabilities
10. Safeguarding adults
11. Safeguarding children
12. Basic life support
13. Health and safety
14. Handling information
15. Infection prevention and control

Figure 1.2: Care Certificate standards

Workforce training can improve the provision of homecare (NICE, 2015a). Higher quality care was associated with greater number of hours of homecare worker training, in a survey of 7,935 older adult homecare recipients (Netten, Jones, & Sandhu, 2007). A systematic review of 152 studies found that effective dementia training for the health and social care workforce included face-to-face participation, theory-based learning that also draws on the roles and experience of staff, supports the application of practice-based learning and provides a structured guide or tool to facilitate care practice (Surr et al., 2017). However, pertaining to the challenges of the homecare sector noted above, there are challenges in providing and resourcing training for homecare workers (Rubery & Urwin, 2011), such as a lack of incentive for agencies to invest in training, given the high rate of staff turnover and employees on zero-hour contracts (Skills for Care, 2020b).

1.2.7.1 Caring for people who lack capacity

Whilst safeguarding is one component of the Care Certificate, it is not specific to people living with dementia. People living with cognitive decline are more vulnerable to risks in the home and forms of abuse, as outlined by The Care Act 2014 (Department of Health and Social Care, 2014). Safeguarding requires homecare workers to protect vulnerable individuals and uphold dignity and respect of people who are less able to communicate needs and preferences.

Caring for people living with dementia who lack capacity to decide whether to accept care can be complex, and homecare workers require skills to be able to meet individual needs. Under the Mental Capacity Act 2005, decisions made on behalf of a person who does not have decision-making capacity, should, if necessary, be made in their best interests, respectfully balancing the person's feelings and wishes with the need to keep them safe (Care Quality Commission, 2020). A key consideration for homecare workers is therefore to find a balance between autonomy, choice, and duty of care for people living with dementia, including those who lack capacity.

1.2.8 Existing dementia skills training programmes

There is an apparent need for specialist dementia training programmes to address many of the challenges associated with homecare provision for people living with dementia. In 2015, Health Education England developed a Dementia Training Standards Framework (Skills for Health, Health Education England, & Skills for Care, 2015) as part of a national effort to implement quality dementia training and education for the UK health and social care sector. The training content in the three-tiered framework was set as the gold-standard needed to deliver good quality dementia care and comprises training on dementia awareness (tier 1; to be completed by all staff), knowledge, skills and attitudes (tier 2; for staff working in social care providing direct support to people living with dementia) and a third tier for key staff or 'experts' working in leadership roles with people living with dementia, such as managers and social care leads.

Some homecare organisations include the Alzheimer's Society's 'Dementia Friends' information sessions as part of their mandatory staff training. The Dementia Friends

initiative was launched in response to the Government's Challenge on Dementia (Department of Health, 2015c; Department of Health and Social Care, 2012a). It aims to create a national social movement by increasing dementia awareness and 'friendliness' through free information sessions that are accessible to anyone; from individual members of the public, to staff within corporate organisations, to the health and social care workforce (Alzheimer's Society, 2017a). Becoming a Dementia Friend involves completing basic dementia awareness training via a short online video or attending a more in-depth information session run by other Dementia Friend volunteers.

1.2.8.1 Evaluating dementia-specific training programmes

An audit of dementia education and training programmes sought to establish whether existing training programmes met the outcomes set by Health Education England's Dementia Training Standards Framework (Smith et al., 2019), reporting on findings from 386 training packages. Of these packages, only 25% were accredited; these included academic or vocational accreditation such as National Vocational Qualification (NVQ). While more than 70% of the training packages covered the learning outcomes of Health Education England's Framework around increasing general awareness of dementia for all staff (i.e. tier 1), less than 40% targeted material relevant to staff with direct regular contact with people living with dementia, or for those in leadership roles (i.e. tiers 2 and 3).

Building on this audit, a recent survey conducted by Parveen et al. (2021) sought to explore the impact of existing dementia training programmes on health and social care staff in the UK. This was based on data from 553 respondents, who had completed one of 18 dementia education and training programmes deemed of interest by the authors (Parveen et al., 2021) in the past five years; these programmes were identified in the audit by Smith et al. (2019). Results showed that at least 75% of Health Education England's Framework were met by these 18 training packages, with the most prevalent subjects covering person-centred dementia care (83%) and communication interaction and behaviour in dementia care (83%). However, the survey identified a limited impact of dementia training on the knowledge, attitudes or confidence of social care staff. The authors suggested factors beyond the scope of

existing training that had a potentially greater impact on staff, including organisational support, promotion of staff autonomy and trust, and individual factors such as staff burnout; positing that dementia training programmes should focus on these too.

1.2.8.2 Dementia-specific training for the homecare workforce

Focusing on dementia-specific training for the homecare workforce, a review of eight studies by Goh, Gaffy, Hallam, and Dow (2018) found a paucity of literature on evidence-based specialist dementia training programmes. The authors found that homecare workers valued the involvement of people living with dementia in facilitating training, as in one programme that focused on care provision for people with young onset dementia (Smith, Ooms, & Greenwood, 2017). This work built upon an earlier review by Cooper, Cenko, Dow, and Rapaport (2017) which looked more broadly at the effectiveness of training interventions for homecare staff supporting older homecare clients. This review highlighted a commonality in effective training elements with interventions for care home staff, such as staff being supported to get to know and connect with their clients living with dementia (Rapaport, Livingston, Murray, Mulla, & Cooper, 2017).

The Broadening Our Understanding of Good Homecare (BOUGH) project (Pollock et al., 2020; Schneider et al., 2019; Turner et al., 2018), sought to understand the scope and nature of good homecare for people living with dementia in England, to inform policy service development and homecare workforce training. The researchers worked with one homecare agency, assessed as 'outstanding' by the CQC (Turner et al., 2018) and are continuing to publish their findings and guidance for homecare workforce training. I will discuss the BOUGH project in more detail below [see section 1.2.7.2: Ethnography in dementia research], as an ethnographic study of homecare.

The Promoting Independence Through Quality Dementia Care at Home (PITCH) programme was recently developed in Australia in collaboration with homecare staff, people living with dementia and family carers (Polacsek et al., 2020). It sought to produce an evidence-based intervention aimed at increasing the skills and confidence of homecare workers in delivering good quality care that promotes quality of life,

independence and reduces family carer stress (Polacsek et al., 2020). The training programme is currently being evaluated in a RCT.

1.2.9 Theoretical frameworks

In this section, I introduce two key theoretical frameworks pertinent to understanding and conceptualising homecare work and support for people living with dementia. I consider the application of emotional labour theories and the concept of power in understanding care work and provision in the home setting.

1.2.9.1 Emotional labour theories of care

Given the high prevalence of female workers within the care sector, I have found feminist-driven emotional labour theories of care relevant to my research. Homecare, and care work in general, involves a high degree of emotional intelligence and interpersonal skills, yet such qualities are undervalued in a capitalist economy (i.e. time-and-task models of care) (Glenn, 2010), and are not reflected in the level of support and training homecare workers receive (Bailey et al., 2015).

There is a longstanding debate that the 'caring' nature of care work cannot truly be performed if the work is motivated by financial reward, rather than altruism. Lane (2017) posed the question of whether care is therefore defined by task (i.e. what one does) or affect (i.e. how one feels)? The commonly commissioned time-and-task approach defines homecare by the tasks care workers must complete, whilst good quality homecare for people living with dementia has, in contrast, been largely associated with the emotional and relational dimensions of care – i.e., the emotional labour.

The 'prisoner of love' framework argues that employers exploit the intrinsic caring motivations of care workers, providing minimal rewards (i.e. low pay) and using women's perceived job satisfaction in helping others to justify tolerating poor pay and working conditions (Folbre, 2012; Rubery & Urwin, 2011). Emotional labour theories have previously focused on nursing and the nurse-patient relationship (i.e. Bailey et al., 2015), however the intimate environment in which homecare is

delivered presents an intriguing and under-researched context of care in relation to emotional labour.

1.2.9.2   Foucault and power in homecare

Theoretical frameworks concerning the concept of power in care work emphasise power disparities between care providers and recipients. Drawing upon the work of Foucault (1984), I considered the notion of power as it exists in everyday relationships, specifically relationships involved in care work, and the productivity of power; in the sense that power serves not only to repress, but also has the ability to empower. Hayward (1998) extended this theory, conceptualising power as boundaried, in that it can both enable and inhibit possibilities for action, and elucidates a person's awareness of these boundaries in order to shape them.

Empowerment and powerlessness were two paradoxical concepts applied to frontline health care assistants in an ethnographic study by Scales and colleagues (2017). The authors considered how working within a person-centred care model empowered care staff by placing them as experts, given their extensive knowledge of their patients, yet at the same time, the health care assistants were perceived to be marginalised by their low hierarchical positioning amongst the broader multidisciplinary team of nurses and other professionals. Similarly, as observed by Kontos and colleagues (2011) in a residential support setting for people living with dementia, organisational rules and demands often took precedence over person-centred care, resulting in some staff breaking rules in order to promote individualised care for residents.

Whilst the theoretical concepts of power and empowerment have largely been applied to health care and residential settings, they are likely to apply also to homecare. Homecare workers' knowledge of how clients live in their own homes should place them as experts to deliver person-centred care. Yet in reality, homecare workers are governed by the same organisational constraints observed in residential settings (i.e. what time to get the client out of bed) that undermine a personalised, person-centred approach. As Scales and colleagues (2017) purported in their work with health care assistants in residential settings, it is plausible that

homecare workers too, carry the burden of being disempowered by organisational parameters, whilst being in a position to enact person-centred care (Scales et al., 2017). Although homecare workers cannot change organisational practices, they can learn and adopt strategies to use during visits to promote person-centredness and independence in their clients where possible.

1.2.10 Ethnography

Given the interpersonal and complex nature of homecare for people living with dementia, I decided upon team-based ethnography as an appropriate exploratory method. Ethnography is the study of social interactions and behaviours that occur within communities or groups, stemming from the field of anthropology in the 1900s (Reeves, Kuper, & Hodges, 2008). The use of ethnography enables researchers to become more deeply immersed in their field of study and conduct more impactful research (Baim-Lance & Vindrola-Padros, 2015). As a method, ethnography is fundamentally a way of relating to others, defined by its ability to reach beyond understanding who relations occur between, and examine the quality of those relations (Darrouzet, Wild, & Wilkinson, 2009).

While various methods of data collection are typically carried out under the umbrella term of ethnography, participant observations are considered to be the foundation for such research (Schensul, Schensul, & LeCompte, 1999). The term 'participant observation' describes the fieldwork approach of collecting data through participating in and observing the communities of interest (DeWalt & DeWalt, 2011). The observer's level of participation in the 'field' can range from non-participant (observing only) to fully participant in the scenario of interest (Gold, 1958). Use of the term 'non-participant observer' can be debated however, as the observer's presence alone can be considered as a form of participation, with the potential to impact the field of study (Laurier, 2016).

1.2.10.1 Rapid and team-based ethnography

Conventional anthropological models of ethnography typically involved one sole researcher conducting in-depth observations, in one setting over a long period of time. Contemporary ethnography, increasingly carried out in applied settings such as

health and social care, has been modified to translate research into practice at a faster pace (Johnson & Vindrola-Padros, 2017; Vindrola-Padros & Vindrola-Padros, 2018). With rapid ethnographies, the focus can be on the breadth of research over depth, with less intensive time spent becoming immersed in the field, and the approach can be carried out collaboratively as a team (Knoblauch, 2005). This type of approach can elucidate understandings of practice that would not be uncovered by other forms of data collection, such as surveys or interviews (Bikker et al., 2017). There is no general consensus of time which classifies an approach as 'rapid', but a review of rapid ethnographies reported study durations from five days to six months (Vindrola-Padros & Vindrola-Padros, 2018). Focused ethnography is one type of rapid approach (Knoblauch, 2005; Vindrola-Padros & Vindrola-Padros, 2018).

Team-based ethnography is a collaborative approach where data is collected and analysed by a number of researchers (usually 2-5 people) (Beebe, 2014). Strengths include the ability to collect more data in a shorter period of time, the incorporation of a range of specialised knowledge, counteraction of individual biases, and acknowledgement of power differences and their potential to affect the quality of the research (Andrews, Lyne, & Riley, 1996). Successful team-based ethnography requires researchers to keep comprehensive and detailed fieldnotes to enable clear interpretation, and to be reflexive in acknowledging different individual backgrounds and perspectives within the team (Scales, Bailey, & Lloyd, 2011). Reflexivity is a 'self-conscious' production of knowledge (Baim-Lance & Vindrola-Padros, 2015) and can facilitate the research team to tease out differences in how fieldwork and data collection were approached by each researcher (Bikker et al., 2017).

Reported challenges of team-based ethnography include lack of clarity in relation to team roles, inconsistent data collection, and collective sensemaking in analysis (Vindrola-Padros, 2021b). These can be mediated through researcher training and use of standardised documents, such as an observation guide, to organise and focus the researchers' lens in the field (Bikker et al., 2017). Variation in each researcher's writing style and ability to self-reflect can also make data sharing and communication difficult. Bikker's (2017) ethnographic work in UK primary care settings, highlighted the sensitivity and intimacy of note sharing with other team members. There is some

debate in the literature regarding researchers censoring or altering fieldnotes before sharing them with others, and the potential impact this has on the data and research outcomes (Armstrong & Lowndes, 2018; Vindrola-Padros, 2021b). Creating space and time for team reflection can help to overcome these challenges, by developing trust within the overall team (Bikker et al., 2017; Vindrola-Padros, 2021b).

1.2.10.2 Ethnography in dementia research

Ethnographic participant observations are potentially well suited to exploring homecare (Briggs, Askham, Norman, & Redfern, 2003), and care of people living with dementia, including those with severe dementia (MacLaren, Nelson, Wilkinson, & Taylor, 2017). Direct observations can provide a perspective of lived experience when participants are unable to take an active part in data collection, as required in interviews and surveys (Mansell, 2011).

Researchers have observed people living with dementia in residential care or hospital settings (Sampson et al., 2019; Scales et al., 2017); although seldom in their own homes. The BOUGH project (Schneider et al., 2019) explored the experiences of homecare workers providing care to six clients living with dementia in the community. Two researchers conducted participant observations over a ten-month period, recording fieldnotes from 334 homecare visits. The researchers underwent homecare training and induction in the agency to work as part-time homecare workers, whilst conducting their observations. Triangulating their fieldnotes with other sources of data, including qualitative interviews and homecare workers' diary entries, the researchers developed a theoretical framework to describe 'the subjective world of homecare workers for people with dementia' (Schneider et al., 2019). One pertinent outcome of the study was the authors' recommendation that staff retention could be improved by providing recognition and reward for homecare workers. However as acknowledged by the researchers, observing just six clients in their homes within a single organisation limited their findings.

1.3   Thesis structure

In this chapter, I have presented an introduction to situate my research in the context of the adult social care and homecare sectors for people living with dementia,

discussed key theoretical frameworks and concepts that are pertinent throughout my research, and introduced the ethnographic method I used to explore my research questions. In the next chapter, I state my research aims and objectives. In Chapter 3, I report the findings from my systematic review, exploring methods of observation used in homecare research. This informed the design of the participant observations in my ethnographic study, which I present in Chapter 4, alongside how I triangulated the data to analyse my findings. I then report these findings across Chapter 5 and Chapter 6 and reflect on my experiences carrying out this work in Chapter 7. In Chapter 8, I describe the NIDUS-Professional coproduction process and how my findings informed the training and support intervention. I provide an overall discussion of my thesis in Chapter 9, including implications for policy and practice and the strengths and limitations of my work. I present my conclusions in Chapter 10.

Chapter 2   Aims and objectives

The overarching aim of my PhD was to develop an in-depth understanding of homecare provision for people living with dementia, and the training and support that enables homecare workers to provide care that promotes independence.

2.1   Phase one: Systematic review

1) To review and systematically describe the methodologies that have been used to observe homecare practices (to inform the design of my participant observation study).

2) To explore how observation methods can inform the researchers' understanding of quality of care delivered.

2.2   Phase two: Ethnographic study

1) To learn and understand from the experiences of homecare workers how they can be better trained and supported in their role.

2) To explore how homecare workers enable and/or inhibit independence at home for people living with dementia.

3) To integrate findings from my research to inform the coproduction of the NIDUS-Professional training and support intervention.

Chapter 3   **Phase one: Systematic review**

In this chapter, I present the first phase of my PhD research: a systematic review of observation methods of adult homecare.

In designing the methodology for my ethnographic study (reported in Chapter 4), I conducted an initial scoping of the literature to understand how observations were used to explore care for people living with dementia in the private setting of the home. My initial search of the literature identified few studies specific to dementia care, so I decided to broaden my search and focus my systematic review on exploring observational studies of homecare delivered to adults with any care needs.

A version of this review was published in *Health and Social Care in the Community* in August 2019 (Leverton et al., 2019). See Appendix 1.

3.1 Objectives

I had two key objectives for this review. These were:

1)   To review and systematically describe the methodologies that have been used to observe homecare practices (to inform the design of my participant observation study)

2)   To explore how observation methods can inform the researchers' understanding of quality of care delivered

In understanding quality of care, I used the definition of: 'care that was consistent and enabled the development of trusting relationships between the homecare providers and recipients' (Cabana & Jee, 2004; Denton, Brookman, Zeytinoglu, Plenderleith, & Barken, 2015; Olsson & Ingvad, 2001; Saultz & Lochner, 2005).

3.2 Methods

I registered the protocol for this review on PROSPERO (CRD42018097034).

3.2.1 Search strategy

I systematically searched the literature to identify papers relevant to my research objectives. I carried out an initial search on 14th May 2018 and an updated search on 24th August 2020, using Pubmed and CINAHL databases. I searched Pubmed database using the available terms: "Homecare Services" [MeSH] OR "Home Nursing" [MeSH] AND "Observation*", in addition to CINAHL database using the terms: "Home nursing" [MeSH] OR "Home Health Care" [MeSH] AND "Observation*". I decided to use MeSH terms to incorporate the range of terms applied to homecare and homecare workers. I limited the search to papers involving only adult participants (which I was able to specify as aged 19+ in Pubmed) and did not apply any limitations to the language that the papers were written in. I augmented the electronic search with a forward and backward search of the included papers, and also hand-searched relevant journals. I also consulted experts in the field for any relevant additional papers.

3.2.2 Inclusion criteria and study selection

I included primary research studies that reported using a method of observation to study homecare delivered by homecare workers. Studies where the care being observed was from a family member, volunteer or clinically-trained health professional were excluded. I excluded protocol papers and conference abstracts as these would not contain the full findings of the study.

Firstly, I screened all titles and abstracts of papers identified in the search against the eligibility criteria. A second independent reviewer, Alexandra Burton (AB), screened 10% of these for inter-rater reliability. Of those which met the eligibility criteria, I then read the texts in full and judged which were eligible for inclusion in the review. Again, AB reviewed 10% of the full texts and we resolved any discrepancies at both stages by discussion. I consulted my three supervisors when there was a lack of consensus and we independently read these full texts and agreed together which papers to include in the final sample.

3.2.3   Quality assessment

I used the Qualitative Checklist Section A (Validity) from the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Programme, 2018) to rate the quality of the included papers. Jessica Rees (JR) and I rated the papers from my initial literature search and then Claudia Cooper (CC) and myself rated the quality of papers from the updated search. The checklist comprised of six questions:

1) Was there a clear statement of the aims of the research?

2) Was a qualitative methodology appropriate?

3) Was the research design appropriate to address the aims of the research?

4) Was the recruitment strategy appropriate to the aims of the research?

5) Was the data collected in a way that addressed the research issue?

6) Has the relationship between researcher and participants been adequately considered?

We independently assigned one point per checklist item, so possible scores ranged from 0 to 6. Higher scores indicated higher quality. Any discrepancies were discussed until we reached a shared agreement. Studies were not excluded on the grounds of quality in line with standard practice for qualitative reviews (Briggs et al., 2003; Campbell et al., 2012; Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012).

3.2.4   Analytic method

I carried out a narrative synthesis to respond to the first research aim (see above). For the second research aim, I undertook a qualitative meta-synthesis, guided by the recommendations of Thomas and Harden (2008) and the guidelines of Braun and Clarke (2006). I extracted the results sections (including tables) from the papers and imported them into NVivo software version 11. I inductively open coded all text describing the findings from observation methods. I developed an initial coding framework and agreed upon subsequent themes to respond to research aim two, regarding how methods of observation added to the researchers' understanding of

quality of care. The initial coding framework was discussed with my supervisors, after which I refined it further in an iterative process.

3.3 Results

My initial search in May 2018 identified 848 unique papers. I included 15 eligible papers from 13 research studies in the review. My updated search in August 2020 identified a further 282 papers of which I identified four papers relevant for inclusion; three of these papers reported findings from the same study.

3.3.1 Study characteristics

In total, I identified 19 papers from 15 research studies that were eligible for inclusion [see Figure 3.1 for PRISMA flow diagram]. The papers were from studies in Sweden (n = 4), Denmark (n = 6), Spain (n = 1), Canada (n = 1), UK (n = 3), US (n = 1), Zambia (n = 1) and South Africa (n = 2). They studied homecare for: older people and people with dementia (n = 9), people with chronic illnesses or disabilities (n = 3), HIV/AIDS (n = 3), and people receiving rehabilitative homecare (n = 4) [see Table 3.1 for characteristics of included studies].

3.3.2 Quality appraisal

JR and I agreed on most of the initial, independent quality ratings of papers (Cohen's Kappa = 0.70) and discussed all discrepancies to reach agreement for all ratings. CC and I agreed on the quality ratings for the additional papers found in my updated search. Quality ratings ranged from 3-6, with 15 of the 19 papers scoring 4 or more [see Table 3.2].

Identification

Records identified through initial database searching (n = 1244)

PubMed   n = 955
CINAHL   n = 289

Additional records identified through other sources

(n = 13)

Records after duplicates removed
(n = 1132)

Screening

Records screened
(n = 1132)

Records excluded
(n = 1034)

Not observing care   n = 724
Medical professional/ nurse n=77
Not in the home   n = 83
Child subjects (<19)   n = 67
Family/ volunteer caregiver   n = 66
Conference abstract   n = 4
Protocol paper   n = 13

Eligibility

Full-text articles assessed for eligibility
(n = 98)

Full-text articles excluded
(n = 79)

Child subjects (<19)   n = 2

Family/ volunteer caregiver   n = 10

Medical professional/ nurse   n = 42

Not observing care   n = 19

Not in the home   n = 5

Protocol paper   n = 1

Included

Meets eligibility criteria
(n = 19)

Older persons/ dementia care n = 9

HIV   n = 3

Chronic illness or disability n = 3

Rehabilitation   n = 4

Figure 3.1: PRISMA flow diagram

3.3.3   Research Aim 1

To review and systematically describe the methodologies that have been used to observe homecare practices (Table 3.1)

<u>Observation methods</u>

Terms: The included papers used varied terms to describe their methods of observation. These were 'participant observations' (Bødker, 2018; Bødker, Christensen, & Langstrup, 2019a; Bødker, Langstrup, & Christensen, 2019b; Casado-Mejía & Ruiz-Arias, 2016; Kalman & Andersson, 2014; Rabiee & Glendinning, 2011; Schneider et al., 2019; Tufte & Dahl, 2016), 'observations' (Cloutier, David, Prevost, & Teiger, 1999; Czuba, Sommerich, & Lavender, 2012) and 'field observations' (Cataldo, Kielmann, Kielmann, Mburu, & Musheke, 2015; Glasdam, Henriksen, Kjær, & Praestegaard, 2013; Nielsen & Jørgensen, 2016; Roberts, Philip, Currie, & Mort, 2015; Swedberg, Chiriac, Tornkvist, & Hylander, 2012, 2013; Uys, 2002, 2003). The term 'ethnography' was also used (Bødker, 2018; Bødker et al., 2019a; Bødker et al., 2019b; Cataldo et al., 2015; Schneider et al., 2019).

Structure: I grouped the methods used into structured, guided and unstructured methods. Structured methods used time sampling procedures or structured observational tools (Czuba et al., 2012; Roberts et al., 2015). Tools used were the Two-Dimensional Interaction Scale (2DSIS) (Wai & Bond, 2001) and a social and personal interaction observation schedule developed by the study authors (Roberts et al., 2015). The 2DSIS assessed four categories of social interaction: active participation, active non-participation, passive participation, and passive non-participation (Wai & Bond, 2001). The social and personal interaction schedule recorded types of interactions that took place, such as 'humour' and 'reassurance touch', as well as whether these interactions were instigated by homecare worker or client (Roberts et al., 2015).

Guided methods of observation employed a semi-structured plan to guide field work (Bødker, 2018; Bødker et al., 2019a; Bødker et al., 2019b; Casado-Mejía & Ruiz-Arias, 2016; Cloutier et al., 1999; Glasdam et al., 2013; Kalman & Andersson, 2014;

Swedberg et al., 2012, 2013; Uys, 2002, 2003). For example, in one study, researchers were guided to focus their observations on three key elements: 'the relationship between people', 'mutual satisfaction', and 'body position' (Casado-Mejía & Ruiz-Arias, 2016). Other studies' methods were unstructured, employing an inductive approach to observe how homecare workers provided care in clients' homes (Cataldo et al., 2015; Nielsen & Jørgensen, 2016; Rabiee & Glendinning, 2011; Sundler, Eide, Dulmen, & Holmström, 2016; Tufte & Dahl, 2016).

Observation procedures

Recording the data: In one study, homecare workers wore devices to audio-record home visits (Sundler et al., 2016). In all other studies, researchers observed visits directly (in person). While in most studies researchers sought to record events naturalistically, one study used a technique termed 'think-aloud', where the homecare workers were asked to explain their activities as they performed them (Nielsen & Jørgensen, 2016). In addition to collecting fieldnotes, Uys (2003) reported audio-recording homecare workers on-site with their employer and in staff meetings.

Number of researchers: When reported, the number of researchers observing ranged from one (in five studies) (Bødker, 2018; Bødker et al., 2019a; Bødker et al., 2019b; Czuba et al., 2012; Glasdam et al., 2013; Nielsen & Jørgensen, 2016; Swedberg et al., 2012, 2013), to a team of observers where only one observer was present during each visit (Kalman & Andersson, 2014).

Researcher role: Three studies described observers taking some form of participatory role. In the study by Schneider et al. (2019), two researchers underwent training and induction to the role of homecare worker, collecting fieldnotes as active participants in homecare. Likewise, Casado-Mejía and Ruiz-Arias (2016) described the observers as being 'active members' of the homecare team, though this was not explained further. Two papers from the same study reported observer participation more generally, describing the observers engaging in brief conversations with the homecare workers (Swedberg et al., 2012, 2013). In a non-participatory role, Kalman and Andersson (2014) described the observers as 'shadowing' the care workers with an emphasis on following them as they worked.

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Building rapport: Two of the studies described the observers engaging in a brief 'getting to know' period before the observations commenced (sometimes termed a familiarisation period). This involved the observers engaging in 'small talk' with the homecare worker (Swedberg et al., 2012, 2013), and gaining an understanding of homecare workers' activities before observing them formally (Cataldo et al., 2015).

Time spent observing: (Reported in Table 3.1). Some studies conducted a pre-determined number of observations, e.g. one single visit to each client participant (Uys, 2002, 2003). Another continued observations until they determined that saturation was reached, shortening the length of observations towards the end of the study (Swedberg et al., 2012, 2013). One study reported that the duration of the observations was determined by the client's availability (Glasdam et al., 2013). Some researchers observed homecare workers outside as well as inside the clients' home: within hospital settings and treatment clinics (Uys, 2003), physiotherapy appointments (Glasdam et al., 2013), meetings with their employer (Cataldo et al., 2015; Nielsen & Jørgensen, 2016), training events (Cataldo et al., 2015), as well as travelling with them between their visits (Nielsen & Jørgensen, 2016).

Recording data: Studies employing structured methods of observation collected data during visits (Czuba et al., 2012; Roberts et al., 2015). In other studies, researchers made brief notes during observations, which they wrote up fully afterwards (Rabiee & Glendinning, 2011; Swedberg et al., 2012, 2013), or wrote all notes directly after the visits (Kalman & Andersson, 2014; Uys, 2002, 2003). Sometimes, short unplanned interviews with homecare workers, clients and family members during the observations were used to enrich fieldnotes (Glasdam et al., 2013; Swedberg et al., 2012, 2013). In one study, notes were recorded using a laptop computer during visits, as this was considered less intrusive than the original method of hand-writing notes during the observation session (Glasdam et al., 2013). Only two studies explicitly stated that observers recorded their own reflective stance (Cataldo et al., 2015; Kalman & Andersson, 2014).

Validating and triangulating findings: One study included homecare worker participants in the analysis of findings (Casado-Mejía & Ruiz-Arias, 2016) and another

conducted the analysis as a team (Schneider et al., 2019). In one study, three independent raters conducted the initial coding of transcripts (Roberts et al., 2015). None of the other papers explicitly reported involving a rater other than the observer in the evaluation and analysis of fieldnotes or observation data. Only one study used a specific strategy to validate findings from observations (Swedberg et al., 2012, 2013). The researchers evaluated the authenticity of the observations by judging against two criteria: the impact of the observer's perspective (i.e. if the situation observed would occur regardless of the observer's own perspective) and the observer's presence (i.e. if the interactions between those observed would occur without their knowledge of being observed).

All but two studies (Kalman & Andersson, 2014; Sundler et al., 2016) triangulated observations with other sources of data. These included interviews (Bødker, 2018; Bødker et al., 2019a; Bødker et al., 2019b; Cataldo et al., 2015; Cloutier et al., 1999; Glasdam et al., 2013; Nielsen & Jørgensen, 2016; Roberts et al., 2015; Schneider et al., 2019; Uys, 2002), focus/discussion groups (Czuba et al., 2012; Tufte & Dahl, 2016) or both (Casado-Mejía & Ruiz-Arias, 2016; Rabiee & Glendinning, 2011; Swedberg et al., 2012, 2013). The study by Schneider et al. (2019) employed five complementary methods of data collection. In addition to participant observations, they asked homecare workers to keep diaries, conducted interviews, and collected survey and documentation data.

Quantitative methods: Four of the 19 papers reported quantitative results in addition to qualitative observation findings (Cloutier et al., 1999; Czuba et al., 2012; Uys, 2002, 2003). In two papers, these methods were used to quantify how much time homecare workers were engaged in activities that were physically demanding during visits (Cloutier et al., 1999; Czuba et al., 2012) and two papers from the same study reported the frequency or timing of visits (Uys, 2002, 2003).

Table 3.1: Characteristics of observation methods employed by included papers

Study and country	Care need population	Number of homecare workers	Number of care recipients	Structure	Aims and objectives	Total Time spent observing	Triangulated data sources	Qualitative data analysis
Swedberg et al. (2012) *(Sweden)* **Swedberg et al. (2013)** *(Sweden)*	Chronic illness or disability	19	4	Guided	To understand perspective of patients receiving 24-hour homecare	78-hours over 17 visits	Interviews	Grounded theory
					To explore how homecare workers manage homecare			
Czuba et al. (2012) *(USA)*	Chronic illness or disability	17	36	Structured	To explore risk factors for homecare worker injury and test interventions for homecare workers	54-hours over 611 observation samples	Focus groups	Frequency analyses
Casado-Meja & Ruiz-Arias (2016) *(Spain)*	Older people and people with dementia	not reported	9	Guided	To explore immigrant care workers', care receivers' and family members' relationships	Spread over a 2-year period	Interviews; Discussion groups	Categories analysis
Cloutier et al. (1999) *(Canada)*	Older people and people with dementia	6	21	Guided	To identify and reduce risk and constraints for homecare workers	30-hours over 22 visits in 5 days	Interviews	Descriptive
Nielsen & Jørgensen (2016) *(Denmark)*	Older people and people with dementia	16	not reported	Unstructured	To explore homecare workers' engagement and role meaning	81-hours	Interviews	Thematic analysis

Sundler et al. (2016) *(Sweden)*	Older people and people with dementia	19	43	Unstructured	To explore communication challenges between homecare workers and clients	100 audio recordings, mean = 16 minutes	None	Hermeneutical phenomenological approach
Tufte & Dahl (2016) *(Denmark)*	Older people and people with dementia	8	69	Unstructured	To understand how homecare workers manage their daily duties	Across 'almost 100 visits'	Focus group interviews	Grounded theory and reflexive interpretation approach
Kalman & Anderson (2014) *(Sweden)*	Older people and people with dementia	7	23	Guided	To explore strategies used to deliver intimate care	Across 37 visits in 4 days	None	Inductive analytical approach
Glasdam et al. (2013) *(Denmark)*	Older people and people with dementia	2	1	Guided	To understand client involvement in homecare	Across 8 days over 3 weeks	Interviews	Constructed analytical categories, guided by theoretical framework
Roberts et al. (2015) *(UK)*	Older people and people with dementia	4	6	Structured	To observe interactions between clients and workers, and what clients value in these interactions	1 visit per patient, duration 30 – 75 minutes	Interviews	not reported
Schneider et al. (2019) *(UK)*	Older people and people with dementia	not reported	6 households	not reported	To understand what good domiciliary care looks like	334 care visits over 10 months	Interviews; Diaries; Survey data; Document analysis	'Order of worth' framework analysis
Cataldo et al. (2015)	HIV/AIDS	48	31	Unstructured	To observe how the introduction of	not reported	Interviews	not reported

Author (Country)	Topic			Interview	Aim	Observation	Methods	Analysis
(Zambia)					antiretroviral medication affected workers' role & client/family relationships			
Uys (2003) *(South Africa)*	HIV/AIDS	15	not reported	Guided	To assist in preparing homecare workers and inform policy to address service provision limitations	not reported	Interviews; Recording onsite meetings; Questionnaires	Template analysis
Uys (2002) *(South Africa)*		16			To describe practice of homecare workers	25 visits	Interviews	Descriptive
Rabiee & Glendinning (2011) *(UK)*	Rehabilitation	not reported	not reported	Unstructured	To explore the practice of reablement services and what may influence effectiveness	26 visits	Interviews; Focus groups	Framework approach
Bødker (2018) *(Denmark)*	Rehabilitation	not reported	8	Guided	To explore how elder-care professionals translate the notion of potentiality into practice	150-hours, observing each older person 3-7 times	Interviews; document analysis	Thematic Abductive Analysis
Bødker et al. (2019a) *(Denmark)*					To explore the normative dynamics and implications of care transitions		Interviews	Situational Analysis approach
Bødker et al. (2019b) *(Denmark)*					To explore reablement in relation to functional decline in understanding what independence in old age means and how to achieve it			Thematic Abductive Analysis

Table 3.2: Quality appraisal using the CASP Qualitative Checklist, Section A

Paper	Qualitative checklist criteria						Total score (out of 6)
	1	2	3	4	5	6	
Casado-Meja & Ruiz-Arias (2016)	Y	Y	Y	Y	Y	Y	6
Cloutier et al. (1999)	Y	Y	Y	Y	Y	N	5
Nielsen & Jørgensen (2016)	Y	Y	Y	Y	Y	N	5
Rabiee & Glendinning (2011)	Y	Y	Y	Y	Y	N	5
Roberts et al. (2015)	Y	Y	Y	Y	Y	N	5
Swedberg et al. (2012, 2013)	Y	Y	Y	N	Y	Y	5
Tufte & Dahl (2016)	Y	Y	Y	Y	Y	N	5
Bødker (2018, 2019a, 2019b)	Y	Y	Y	Y	Y	N	5
Schneider et al. (2019)	Y	Y	Y	Y	Y	N	5
Cataldo et al. (2015)	Y	Y	N	N	Y	Y	4
Czuba et al. (2012)	Y	Y	Y	N	Y	N	4
Sundler et al. (2016)	Y	Y	Y	N	Y	N	4
Glasdam et al. (2013)	Y	Y	N	N	Y	N	3
Kalman & Anderson (2014)	Y	Y	Y	N	N	N	3
Uys (2002, 2003)	Y	Y	Y	N	N	N	3

3.3.4   Research Aim 2

To explore how observation methods can inform the researchers' understanding of quality of care delivered?

I identified three key themes that responded to this research question. These were: 1) The impact of care delivery and organisational factors; 2) Observing relationships and communications; and 3) People and places behind closed doors. The examples given in this review to support these themes were extracted from the qualitative observations presented in the included papers.

3.3.4.1   Theme one: The impact of care delivery and organisational factors

In this theme, I considered practices adopted by care agencies or employers of homecare staff and their impact on care delivery. Such practices included scheduling of visits and time allocated for clients, as well as support provisions for homecare workers.

3.3.4.1.1   Subtheme A: The role of time

The observers considered how time availability, or lack of, affected care delivered to clients. In some situations, such as the example below, homecare workers were scheduled to visit clients for short periods of time; the consequent time constraints appeared to negatively affect quality of care. Limits of time could detract from clients receiving person-centred care. Instead, homecare workers prioritised getting necessary tasks completed in the allocated time:

'The client has finished his dialysis and suddenly remembers he had forgotten to fold swabs… [Homecare worker] says he should have thought of that earlier… instead of talking. There is no time for folding swabs now; he has to take his shower.' (Glasdam et al., 2013)

In studies where homecare was delivered to support reablement, time-limited care models were seen as 'insufficient' and were observed as a source of frustration for clients. In one paper, clients received a time-limited 8-week reablement programme (Bødker et al., 2019a).

In other observations, good quality care seemed to equate to care that was delivered without apparent time constraints, despite all visits being time-limited. This occurred where homecare workers 'figuratively left time outside when entering the home' (Tufte & Dahl, 2016). Clients received care that was more person-centred when homecare workers' attention was not governed by time:

'The [homecare workers] rarely checked their watches or mentioned how much time they had for the visit and instead took time to listen to the client in spite of tight schedules.' (Nielsen & Jørgensen, 2016)

In other situations, homecare workers appeared to sacrifice personal time for their work. While this could be virtuous in terms of providing good quality care, it also came at a cost to the care workers, such as giving up their own unpaid time for clients:

'Often patients had favourites, typically among the experienced [homecare workers], who were then willing to make personal sacrifices. …Being a favourite could lead to disadvantages, such as diminished control over one's own working hours.' (Swedberg et al., 2013)

'… exerting effort to get to know the patients closely, spend extra time socialising and acting much as they would if the patients were their own family members.' (Nielsen & Jørgensen, 2016)

This occurred more often where homecare workers had established close relationships with their clients, as inferred from the quote immediately above.

3.3.4.1.2 Subtheme B: Organisational context

Organisational systems such as visit scheduling and support for homecare workers were perceived to impact care delivery. Insufficient training and systems of support for homecare workers could negatively affect the care workers' ability to provide good quality care, in addition to impractical documentation systems as noted in the first example below:

'One of the home helpers would for instance document the course of each reablement training session by hand on a printout of the reablement plan placed on

the older person's coffee table, although this should have been digitally reported in

the municipality's documentation system.' (Bødker et al., 2019b)

'Calling [the office] when in need of help on a Friday evening, one [homecare

worker] experienced that nobody answered in spite of the fact that she had been

told to use this number, even on evenings and weekends.' (Swedberg et al., 2013)

Organisational practices for scheduling homecare workers' visits were important in supporting continuity of care for clients. Bødker (2018) observed how clients' reablement visits would be paused when the assigned homecare worker took days off or went on holiday leave, noting that it was 'difficult for substituting care workers to take over'.

3.3.4.2 Theme two: Observing relationships and communications

In this theme, I explored how observers captured the relationships that took place between homecare workers, their clients and sometimes their family members. Across many of the papers, observers described how homecare workers navigated relationships that were perceived as professional, yet also sometimes intimate and close. Being present during homecare visits, the observers captured elements of friendship and reciprocal warmth that went beyond the professional role. Homecare workers were likened to friends of their clients, or described as blended in like part of their family:

'In almost all households visited, the [homecare workers] were welcome friends,

who talked, joked and became part of the family life.' (Uys, 2002)

'Alice and her home helper Betty were quick to develop a friendly tone with

each other, and to much amusement for them both they shared the secret of using

"forbidden cleaning products."' (Bødker et al., 2019a)

Close homecare relationships were not always welcomed or desired by clients. In one study by Schneider et al. (2019), the observers noted a conversation with a homecare worker describing a client whom it had been difficult to build a relationship with:

'[Co-worker] told me that Christine is not like other clients she visits… She stressed, it's not that she's unfriendly, she's just not interested in chatting: she is very "as you are dear". [Co-worker] said that even if you visited her every day for a couple of years, you probably wouldn't be able to build up much rapport either'. (Schneider et al., 2019)

Observations also captured the role of homecare workers in maintaining clients' independence as seen in the first quote below (Kalman & Andersson, 2014), and the strategies used to uphold dignity, in the latter quote (Tufte & Dahl, 2016):

'Usually, if the recipients were able to do some of the intimate washing themselves, the care worker assisted with the washcloth and then left the bathroom.' (Kalman & Andersson, 2014)

'[Client] is walking around in his underwear when the care workers enter his home. He has wet his underpants as he suffers from cystitis, and the care worker immediately tries to cover him up by pulling down his singlet.' (Tufte & Dahl, 2016)

Homecare visits were also, at times, challenging for homecare workers. The observers captured how the care workers managed during these situations and the strategies they employed to provide good quality care to their clients. In one paper, the observers were able to understand why the homecare workers seemed to 'interrogate' their clients, in the interest of their health and wellbeing:

'Some clients pretend to have swallowed the tablets yet haven't; they keep the tablets under their tongue and wait for the caregiver to leave so that they can spit it out. It is for this reason that caregivers use a technique of interrogating the client immediately after taking their medication.' (Cataldo et al., 2015)

Some papers described other challenging aspects of the homecare worker-client relationship, including when clients were rude or disrespectful towards the homecare worker (as in the first quote below), or where homecare workers were perceived to act unprofessionally in their role (as in the second of the quotes below):

'The lady [client] never called her [homecare worker] by her name. She referred to her as "this"'. (Casado-Mejía & Ruiz-Arias, 2016)

'In one extreme case, even though a female care recipient had a rather big bathroom with space enough for two care workers to assist her, she was placed in the hall, naked and dressed there.' (Kalman & Andersson, 2014)

Observers captured non-verbal communications between care workers, their clients and family members that were significant to understanding the relational dynamics of care and the importance of homecare for clients. These included expressions of care and empathy via touch, the familiarity between homecare worker and client through mirrored behaviours, and expressions of relief and gratitude through facial expressions:

'As we drove into the yard… a middle-aged woman came running to us from the road. It was the mother of the client. … As she reached us, she was crying with relief that we had arrived so timeously.' (Uys, 2003)

'"Come here darling." The [homecare worker] touches the patient gently and turns her towards herself. The other [homecare worker] continues with the washing procedure.' (Swedberg et al., 2012)

3.3.4.3   Theme three: People and places behind closed doors

In this theme, I consider aspects of homecare that may be out of reach to non-observational methods. Through their observations, the observers captured clients who would perhaps be less able or unlikely to take part in other forms of data collection, for example due to poor health, in addition to observing care situated within the intimate context of the home environment; unique to this methodological approach.

3.3.4.3.1 Subtheme A: Capturing all voices

Observers captured homecare visits with clients requiring care for various needs and with varying severity of symptoms. Some of the clients receiving homecare were in poor health, had physical impairments, or diminished cognitive capacity:

'When we got there, the mother was just sitting in front of the house… with no energy to do anything except the most basic movements.' (Uys, 2002)

'For some older adults with chronic pain, opportunities to socialise… or leave the home and interact with others were very limited. For these individuals, the home visit provided personal contact that would otherwise be missing from their lives.'
(Roberts et al., 2015)

The observers were able to represent the experiences of such clients receiving homecare, making them visible in research, whereas they may have been missed in other forms of data collection.

3.3.4.3.2 Subtheme B: The home environment

Observations also captured how the home environment influenced care or care strategies, or raised health and safety concerns for the homecare workers. This included where clients lived in apartment buildings with multiple doors to navigate to go outside, and where homes had small bathrooms that were not well adapted for care tasks. Where homes were not well adapted for care, the environment could negatively impact the care workers' ability to provide dignified care and posed health and safety risks for the homecare workers:

'The wife tells that the client has not always been able to get a bath because of the design of the bathroom that meant bad physical working positions for the care staff.' (Glasdam et al., 2013)

In some papers, the observers described the homecare worker using humour as a strategy to make light of a potentially uncomfortable situation for both the client and the care worker:

'The bathroom was extremely narrow. She tried to cheer the man up by making small talk as she helped him to the small bathroom, and when crossing the threshold, an awkward pose was struck. "Now we have to do a dance", the care worker said laughing, twisting the man on to the toilet.' (Kalman & Andersson, 2014)

Sometimes, the requirements of the caring situation prompted changes to the clients' home environment. In these situations, clients and their family members often felt they did not have control in the matter, if they were to continue receiving homecare:

'The client's wife stands up against some of the iterations because any physical alteration in the home is a visible sign of their abnormal situation.' (Glasdam et al., 2013)

'"Everyone gets to decide except me", one patient said when the [homecare workers] decided where to place the furniture in her own apartment.' (Swedberg et al., 2012)

3.4   Discussion

Responding to the two aims of this review, I conducted a narrative synthesis to describe the methodologies that have been used to observe homecare practices, followed by a qualitative meta-synthesis to explore how methods of observation informed the researchers' understanding of the quality of care delivered. The overall aim of the review was to inform the design of the participant observations in my ethnographic study (presented in the next chapter). I identified 19 papers from 15 studies that used observational methods to observe homecare delivered to adult care recipients.

All papers included in my review captured qualitative findings to explore their research questions, with four papers also collecting quantitative data. Observations are largely qualitative in design. While quantitative measures such as surveys are

common in evaluating health and social care practices, qualitative methods enable a deeper and richer understanding of every day phenomena (Johnson & Onwuegbuzie, 2004), providing the researcher with insight into the 'who, what and where' of experiences (Sandelowski, 2000). My findings in this review provide additional support in purporting that observational methods are well suited to conducting research on care provided in the home setting. Observations enabled the researchers in the included studies to delve further into understanding the meaning behind events (Briggs et al., 2003), and explore the impact of the home environment on care delivery, as well as the experiences of people who may have been otherwise missed from research.

While qualitative interviews and focus group methods have been used frequently to study homecare (Barken, Denton, Plenderleith, Zeytinoglu, & Brookman, 2015; Lovelock & Martin, 2016; Yeh, Samsi, Vandrevala, & Manthorpe, 2018), methods of observation have to date been used less widely, particularly in studies of people living with dementia. This review highlighted clear benefits of direct observations in capturing the relationships and interactions between homecare workers, clients and possibly family members. In particular, capturing non-verbal behaviours that signified compassion, relief or closeness in relationships that are not typically visible when employing other methods. This may be particularly important when studying people living with dementia who have reduced or diminished cognitive capacity.

My findings demonstrated that care quality and delivery in the home setting is influenced by interactions between homecare workers, clients and the physical environment, in addition to organisational practices. Across the studies included in this review, observations enabled these interactions to be recorded in context. In studies employing qualitative interviews, homecare staff have reported their recollections and interpretations of care delivery and the associated challenges (Butler, 2009; Ryan, Nolan, Enderby, & Reid, 2004). As such, the pressure of time for homecare workers is not a new finding, however observational methods were able to elucidate how these pressures are absorbed or made explicit. Observing care directly can be triangulated with other information. For example, problems to which a homecare worker may have become habituated and thus ceased to notice

something, such as how the home environment is negotiated as a care setting and as a private home, may be more striking to an outside observer.

3.5   Implications

3.5.1   Methodological design and observation structure

From this review, I reflected on the importance of the structure of the observations (i.e. structured, guided or unstructured). From this, I considered which method would be most suited to my ethnographic study, where observations were to be carried out by more than one researcher; as a large study was planned for this research at the funding submission stage. I also considered which structure would be most appropriate for observing people living with dementia. From this review, I perceived structured observations were likely well suited to research concerning safety/risk or when quantifying frequencies (e.g. of care tasks performed by homecare workers). Guided and unstructured methods were likely to be better suited to more exploratory research such as my ethnographic study. However, this review highlighted limitations concerning inter-rater reliability when there are multiple researchers involved that were important to consider and try to account for in my methodological design; thus, I decided upon a guided structure to reduce inter-rater variance (see Chapter 4).

3.5.2   Observer participation

Most of the included studies did not specify the role of the researchers in the observed interactions. Gold (1958) described four roles that a researcher might take, in terms of their level of involvement or active participation in the field. The 'complete participant' blends in amongst their participants, to the extent that their genuine identity is unknown in the field. While the 'participant-as-observer' is similar to the 'complete participant', the key difference is that the participants are aware of the researcher's presence as an observer. This was most similar to the role adopted by the observers in the study by Schneider et al. (2019). The 'observer-as-participant' role is described as brief observations of participants, where the observer has less active participation in the field. This aligns with the role that I adopted in the design of my participant observations. Lastly, Gold (1958) described the 'complete observer'

as one who is entirely removed from the field, to the extent that participants are unaware of the observer's presence and do not know they are being observed. Applying these varying levels of participation to observing care in the home setting, the 'complete observer' role is not ethical or practical. Entering the private sphere of the home requires the researcher's presence to be known to participants. Beyond this, some level of participation or engagement with participants, such as those living with dementia and with homecare workers may be necessary to provide reassurance and gain trust, while finding a balance with maintaining the authenticity and validity of the observed care scenario. Gaining trust is likely to be of particular necessity when observing homecare workers, given that their work often comes under scrutiny (The King's Fund, 2018b).

While familiarisation visits can enable observers to build rapport and gain the trust of their participants prior to recording fieldnotes, most studies I reviewed did not explicitly report a familiarisation or rapport-building period. Burns (2000) suggested that observers refrain from note-taking for an initial period, to allow all involved to become used to having an observer present. The benefits of rapport building and normalisation may be negated by research provisions, namely time and funding. This may be particularly pertinent where just one or two observation visits are planned. I considered a period of familiarisation important to incorporate into my study design, to begin to establish rapport and trust with homecare workers, clients living with dementia and their family members.

3.5.3 Validation and credibility

In most of the studies I reviewed, one researcher conducted all observations, and few studies reported methods used to validate their findings, i.e., through seeking different perspectives or collecting data beyond the original observer's account. Observations are, by definition, from the point of view of the observer, but incorporating elements of participant validation or triangulating findings with other researchers, as well as with other sources of data collection, can evaluate and enhance external validity (Flick, 2004). All but two of the papers I reviewed triangulated participant observations with other sources of data collection, such as

qualitative interviews or focus groups. Whilst my ethnographic study design included qualitative interviews, visual elicitation and case documentation (see Chapter 4), this review highlighted the need to also consider how to enhance the validity and quality of my findings. Mays and Pope (2000) suggested incorporating methods such as respondent validation (checking the researcher's account against the participant's), giving attention to 'negative cases' (searching for contradictions in the data) and reflexivity (giving consideration to how the research process has impacted the data collected), in addition to triangulation. In most of the papers I reviewed, the researchers did not directly report the impact of their presence during the observations, nor in the data collected. The researcher's reflective stance is highlighted as key in the process of ethnographic research (Vindrola-Padros & Vindrola-Padros, 2018), considering how the observer's emotions and rationality may impact on their observations (Watts, 2011).

3.5.4 Terminology

Finally, this review adds to the debate concerning a lack of consensus regarding the terminology used to describe methods of observation. In the 19 papers I reviewed, four broad terms were used to describe what was ultimately the same general method employed across all studies. Vindrola-Padros and Vindrola-Padros (2018) created a typology of the definitions applied to rapid ethnographies, highlighting eight available terms that were used interchangeably and with considerable overlap. They argued that consistent use of terms to report ethnographic and observational methods will enhance conceptual and methodological clarity in research. Inconsistent terminology may reduce the visibility of important research to other researchers. I therefore use 'participant observations' as a consistent term throughout my research.

3.6 Strengths and limitations

To my knowledge, this is the only review to date that synthesises findings from observational studies of homecare. The homecare sector is a rapidly growing workforce globally, yet research seeking to directly observe the nature of such work is limited. An initial scoping review of the literature found a paucity of studies

employing methods of observation to study care for people living with dementia at home. This review highlighted the usefulness of observations as a method of data collection in such research, and its potential to obtain rich and meaningful data that other methods may overlook.

One significant limitation was that as many of the reviewed papers triangulated their observational findings with those sourced through other methods of data collection such as interviews, it was not always possible to distinguish which results were from the researchers' direct observations and which were drawn from other sources. However, where I included example quotes in support of the findings from my narrative synthesis, I used only those quotes that were presented in the papers as observational fieldnotes; although this may have resulted in some examples being excluded where the source was unclear. This reflects the pragmatic nature of ethnography, whereby methods of observation are seldom used in isolation.

3.7   Summary

In this chapter, I have presented phase one of my research: a systematic review exploring the methodologies that have been used to observe homecare practices to inform the design of my participant observation study, and to explore how observation methods can inform researchers' understanding of quality of care delivered.

In the next chapter, I present the methodological design of my ethnographic study in detail. I carefully considered and drew upon what I learned from this review in designing the participant observations to explore care provided to people living with dementia at home.

Chapter 4   **Phase two: Ethnographic study methods**

In this chapter, I describe the method and analytic strategy of the second phase of my PhD research - my ethnographic study. I carried out two forms of qualitative data collection as part of a research team: 1) semi-structured interviews with homecare staff, people living with dementia, their family carers and health and social care professionals, and 2) participant observations with homecare workers as they provided care to clients living with dementia.

This study sought to provide a rich understanding of homecare for people living with dementia, from the perspectives of key stakeholders involved in both its provision and receipt. Two aims of this study were:

1. To learn and understand from the experiences of homecare workers how they can be better trained and supported in their role.

2. To explore how homecare workers enable and/or inhibit independence at home for people living with dementia.

4.1   Research team

The ethnographic data was collected via a team-based approach, by AB, JBD, RHG, PR and myself, as described in Chapter 1. The data collected by each researcher is detailed in my Conjoint Statement [page 9]. Where I use the term 'we' throughout this chapter, I refer to the above-named researchers.

4.2   Study design

My systematic review (Chapter 3) informed the methodological design of the participant observations, which, together with the qualitative interviews, comprised my team-based ethnographic study. In turn, my ethnographic study informed the PPI coproduction process of the NIDUS-Professional training and support intervention for homecare workers (presented in Chapter 8). The full process of informing NIDUS-Professional is illustrated in Figure 4.1.

Figure 4.1: Process informing the NIDUS-Professional intervention

The approach I took to my ethnographic study aligns closest to what has been termed a team-based 'focused ethnographic approach' (Knoblauch, 2005; Vindrola-Padros & Vindrola-Padros, 2018). Focused ethnography is conceptualised as fieldwork that is short in duration but balanced by collaborative and intensive data collection and analytic scrutiny (Knoblauch, 2005). I took this pragmatic approach, in part, due to available time and team collaboration as well as its suitability to social research, particularly given the researcher-observers' backgrounds in psychology and sociology. Prior knowledge of the topic or familiarity with the community of interest is considered a prerequisite for focused ethnography (Knoblauch, 2005).

4.2.1   Participant observation design

I translated key methodological characteristics identified in my review (Chapter 3) into the design and procedure of the participant observations. I have illustrated this in Figure 4.2. To decide on the most appropriate method to explore my research questions, I tried out both structured and unstructured methods in everyday scenarios (e.g. observing colleagues in an office environment, and a group of children

in a home environment). I piloted both a non-participatory time-sampling procedure, as well as a more participatory approach using a trial observation guide. Time-sampled and non-participant observations have been effectively carried out by researchers observing care of people living with dementia in hospital and care home settings (Handley, Bunn, Lynch, & Goodman, 2020; Sampson et al., 2019) and when observing palliative care in the home setting (Walshe, 2020). I felt, however, that structured time-sampling is less suited to capturing naturalistic observations of behaviour and interactions as and when they happen. I also learned early in conducting the participant observations that being a 'non-participant' observer was not always feasible with people in their own homes, as they often wanted to engage in conversation, nor is it compatible with ethno-interviewing techniques (described below).

I decided to use the term 'participant observations' to acknowledge the impact of the observers' presence, and in thinking of participation as fluid, or on a spectrum of varying levels of participation. This is reflective of the variation across different researchers' observation styles, and across different participants and care situations.

Likewise, as I discuss in greater detail below [see section 4.2.2: Epistemological position], the concept of non-participant observation is incompatible with a critical realist/post-positive viewpoint that considers behaviour as changeable within the context it is observed, and therefore the impact of the observers' participation (even just as a present being) is an important dimension to acknowledge. Therefore, the researcher-observers' role can be likened to Adler and Adler's (1987) depiction of a 'peripheral' observer, where first-hand insider perspective is gained without functionally participating in the scenario observed, as well as Gold's (1958) description of the 'observer-as-participant' role, where observations are more formal, and contact with participants is considered brief (as discussed in Chapter 3). However, Gold (1958) presented limitations associated with this role, such as the potential for the observer to misunderstand their participants due to the brief nature of their contact in the field. Familiarisation visits to build rapport and increase comfort between observers and participants may reduce this possibility.

Terms
- Ethnography
- Participants observations

Structure
- Guided observations

Collecting data
- Visits observed in person by researcher-observers

Recording data
- Pen and paper
- Brief jottings during visits, fieldnotes typed-up in full after visit

Time spent observing
- Up to two familiarisation visits and up to five observation visits
- Observations capped at two-hours

Number of participants
- 16 homecare workers with 17 clients living with dementia
- Recruitment ceased once data saturation was reached

Number of researchers
- Three, termed 'researcher-observers'
- One researcher per homecare agency, one researcher per observation

Researcher role
- Conversational but non-interventional, no involvement in care tasks
- Likened to Gold's (1958) 'observer-as-participant' role

Building rapport
- One to two familiarisation visits aimed to build rapport

Validation and triangulation
- Researcher reflexivity, fair dealing, triangulation with interview data

Figure 4.2: Participant observation method informed by review findings

4.2.2   Epistemological position

I approached the data from a position of post-positivist critical realism. Bhaskar's (1978) positivist approach to critical realism provides a suitable lens to view the complexities involved in the health and social sciences. This has particular relevance in Bhaskar's, amongst other philosophical and sociological considerations of human behaviour as fallible or changeable under the contexts in which it is observed (Archer & Archer, 1995; Sayer, 1992). Applying this standpoint to my data, I assumed that what was heard and observed from participants was reflective of an underlying

reality, albeit a reality often mediated by the presence and underlying biases of the researchers (considered in Chapter 7).

Therefore, I considered the qualitative interviews and participant observations as complementary methods; where these told different stories, I reflected on the different realities and how they were mediated, rather than seeking to identify a singular reality. One example of this was where there appeared to be contradictions in what people said and what was seen in practice (i.e. see Chapter 6: Subtheme A: The past versus the present self, where I discuss person-centred care in theory versus in practice).

4.3 Setting, participants and procedures

4.3.1 Ethical approval

This work was carried out within stream one of the NIDUS programme. Approval was obtained from London (Camden and Kings Cross) National Research Ethics Service (NRES) (reference: 17/LO/1713) before I started my PhD.

4.3.2 Ethical considerations

4.3.2.1 The consenting process

Including people living with dementia in research requires safeguards to protect them from harm and to respect their autonomy and agency, including making decisions such as in the consent process (Thorogood et al., 2018). Careful consideration was given to data collection with people living with dementia, given the possibility that cognitive capacity, and therefore capacity to consent, is often impaired and can fluctuate. While the nature of the ethnographic work was rapid, obtaining informed consent from participants was in no way modified to speed up the process. Indeed, considering informed consent as a process rather than a one-off event, is particularly relevant for rapid ethnographies (Vindrola-Padros, 2021a) where data collection may be intensive or burdensome for participants.

All researchers involved in collecting data were trained in assessing capacity, and we adopted Standard Operating Procedures based on the Mental Capacity Act 2005.

When obtaining informed consent, the researchers informally used the 4-stage test of capacity to assess: 1) whether the person was able to understand the information and what the study would require of them, 2) if they were able to weigh up the information, 3) whether they could make a decision about taking part in the study, and 4) whether they were able to communicate their decision. The researchers also ensured that all participants understood that they could decide to withdraw freely, without their care being affected.

When conducting the participant observations, we asked homecare agency managers and homecare workers about whether or not individuals living with dementia had capacity to understand and therefore consent to the research. Where they were unsure of this, we sought to explain the research and obtain the individual's consent in the first instance, to respect their dignity and autonomy (Thorogood et al., 2018). Once the observations began, regardless of whether the person had capacity, the researchers re-visited and re-established consent with participants living with dementia on every visit and on several occasions during the visit, in a process of ongoing consent monitoring (Dewing, 2008b). The researchers also checked with individuals and their homecare worker throughout, that they were comfortable with the researcher being in their home and observing their care (including personal care).

4.3.2.2 Safeguarding

As outlined in the introduction of this thesis, people living with dementia may be at greater risk of abuse (Cooper et al., 2009). As such, it was important for this research to have safeguards in place for reporting concerns about potential abuse or neglect, either described by participants in interviews or observed. Researchers involved in collecting data followed a Standard Operating Procedure to report safeguarding concerns that arose during the study to the Chief Investigator and documented these events in an incident log. Participants were made aware that the only time confidentiality would be breached, was when the researchers had concerns or were made aware of a significant risk to the safety or welfare of the participant or someone else. Any concerns were discussed within the research team in the first instance, and then escalated to the appropriate source, i.e. the homecare agency manager or local authority. There were four incidents raised as concerns by the researchers during the

participant observations, which were reported to the Chief Investigator and discussed with the homecare agency managers to investigate and resolve; no concerns were raised during the interviews.

4.3.2.3 Confidentiality

All information obtained throughout the research was confidential, and measures such as the use of pseudonyms and anonymised ID numbers protected the privacy of participants. Any identifiable information collected in interview transcripts, observation fieldnotes or care plans, such as names and locations, was redacted. Interviews were recorded using encrypted audio-recorders and all data was stored on password-protected files on university computers, which were only accessible to the immediate research team.

4.3.3 Sampling and recruitment

4.3.3.1 Qualitative interviews

We recruited key stakeholders involved in homecare provision for people living with dementia. This included people diagnosed with dementia with capacity to consent and carers (relatives or friends) from three NHS memory services, private and local authority homecare agencies, an Alzheimer's Society Experts by Experience group, and Twitter. Health and social care professionals who were involved in commissioning or planning homecare for people living with dementia were recruited through UCL, four geographically diverse NHS memory services and one local authority, with whom the research team had an existing relationship with. We provided prospective participants with a participant information sheet [see Appendix 2-4] and answered their questions relating to the study, before obtaining their informed consent to take part.

To recruit staff from homecare agencies, we used the Care Quality Commission (CQC) website to identify homecare agencies that were diverse in relation to location and CQC rating. We spoke to agency managers by email or telephone to explain the study and provided participant information sheets to be read by the manager and distributed to office support staff and homecare workers who supported people living with dementia [see Appendix 4]. Staff who were interested in taking part in an

interview contacted us by the phone number or email address provided on the information sheet, or we followed up with agency managers up to one week later and they provided us with contact information for homecare workers who expressed interest. We contacted twelve urban and semi-rural/rural homecare agencies to recruit homecare managers, office support staff and homecare workers who worked with local authority and/or privately funded clients living with dementia. All agencies expressed interest in participating, but we lost contact with one agency with whom we did not conduct any interviews.

I purposively steered recruitment to include people from a range of backgrounds, roles (homecare staff and health and social care professionals), relationships to the person living with dementia (family carers) and experiences of contact with homecare services (people living with dementia), and shift-pattern and client type (homecare staff). Our research team initially telephoned potential participants to explain the study and then sent a participant information sheet by email or post to those expressing interest. We obtained written, informed consent from all participants before conducting interviews [see Appendix 5-6]. Only people living with dementia who had capacity to consent to the research were approached (as judged initially by recruiting services, and subsequently by researchers prior to obtaining informed consent). Homecare workers were included if they supported at least one client living with dementia.

4.3.3.2   Participant observations

I purposively sampled homecare agencies for diversity of location (in urban or rural/semi-rural locations), size of agency (i.e. number of clients), CQC rating, care provision (i.e. agencies with 15-minute visits and agencies with a one-hour minimum visit policy) and client funding (Local Authority or private). Of the eleven homecare agencies participating in the qualitative interviews, we purposively approached seven and provided the agency manager with an information about the participant observations [see Appendix 7]. Of these, one manager declined, and six managers consented, but we lost contact with one of these agencies shortly after, when the consenting manager left the agency. We approached additional agencies that were not involved in the interviews, identifying them via the CQC website and purposively

sampling agencies by location and CQC rating to diversify the sample. We provided a participant information sheet to those where the manager expressed interest from the initial phone call. Of these, one manager agreed for their agency to participate, but two other agency managers expressed preliminary interest that was not sustained.

AB, JBD or I visited the agencies where the manager expressed interest in participating and answered any questions the manager had about the study. Agency managers provided informed written consent for the agency to participate [see Appendix 8]. They were then asked to identify homecare workers who provided regular support to at least one client living with dementia, and to give them and their clients or nominated consultee a participant information sheet [see Appendix 9, 11 and 13]. Homecare workers were invited, but not required, to participate in both a qualitative interview and the participant observations. Those who intended to leave the agency within the next six months were excluded from taking part in the participant observations to ensure we could complete the data collection.

Meetings with homecare workers took place at the agency's office or in the homes of their clients where the participant information sheet was discussed, and informed consent was obtained. When consenting the homecare workers at the client's home, we arranged a prior phone conversation to explain the research in detail and to arrange a date to visit the client's home. In this visit, the information sheets were reviewed in detail and we obtained written consent from the homecare worker, person living with dementia and personal/nominated consultee (if present) at the same time [see Appendix 10, 12 and 14].

Participating homecare workers were asked to discuss the research with their clients before we visited them at home. Either the homecare workers or the agency managers helped to identify potential clients living with dementia with whom we could observe care. We discussed with the agency managers or homecare workers in the first instance, whether the person living with dementia had capacity to consent to take part in the research. Decisions on capacity were ultimately made by the researcher upon meeting with the clients (after receiving training on assessing

capacity – see above). If the person living with dementia did not appear to have capacity to consent for themselves, a family member was contacted and invited to act as personal consultee, or a nominated consultee (i.e. a social worker) was contacted by the researcher to provide their advice on what they considered might be the view of the person living with dementia; and complete a consultee consent form. We also obtained written consent to be observed from family carers, healthcare professionals and other homecare workers who were present during homecare visits.

4.4   Data collection

4.4.1   Qualitative interviews

Interviews were conducted by the research team between March and September 2018. Participants were invited to be interviewed in a private location convenient for them (UCL premises, participants' own homes or places of work). At the start of the meeting, the researcher reviewed the participant information sheet with potential participants and obtained written consent. Participants completed a demographic questionnaire.

Interviews were guided by a semi-structured topic guide. I developed the topic guide sections specific to my PhD objectives, focusing on training and support for homecare workers who care for clients living with dementia. These were added to the existing NIDUS topic guides which asked questions relating to how people living with dementia achieve independence at home and other questions specific to the NIDUS-Family work stream (outlined in Chapter 1). Questions relating to my PhD objectives are presented in Table 4.1. Health and social care professionals and homecare staff were interviewed using the same topic guide, while people living with dementia and family carers had slightly amended versions. People living with dementia and family carer dyads were interviewed together or separately, depending on their preference.

Table 4.1: Semi-structured interview questions

Participant topic guide	Topic	Questions related to my research objectives
Family carers	Independence	o To what extent is the person you care for currently able to live independently at home? o What do you find independence means for the person you care for? What do you feel being independent looks like for them? o What makes it harder/easier for the person you care for to live independently at home?
	Training	Thinking about a training programme for homecare workers who support people living with dementia: o What do you think you and the person you care for would find most useful? o What do you think this should include? o Is there anything you wouldn't want this to include or be like?
Homecare staff **+** **Health & Social Care Professionals**	Independence	o What do you find independence means for your clients living with dementia? What do you feel being independent looks like for them? o What makes it harder/easier for your clients living with dementia to live independently at home?
	Training	Thinking about a training programme for homecare workers who support people living with dementia: o What do you think you and the person you care for would find most useful? o What do you think this should include? o Is there anything you wouldn't want this to include or be like? o What might make it easier/more difficult to implement training for homecare workers working with clients living with dementia? o What might make it easier/more difficult for home care workers to carry out their training in practice?
People living with dementia	Independence	o What do you do to live independently at home? Do you get any help from anyone else (paid carer/family member)? What do they do? o What can make it harder/easier to stay independent?
	Training	Thinking about a training programme for homecare workers who support people living with dementia: o What do you think this should include? o If you could, is there anything you would like to tell/teach/show homecare workers or care agency managers?

The interviews lasted around one-hour and participants were offered a £20 voucher for their time. Interviews were audio-recorded and transcribed verbatim by a professional transcription company. I made an in-situ decision about the final sample size (Braun, Clarke, Hayfield, & Terry, 2019) and ceased recruitment when I judged the participant sample to be sufficiently diverse to ensure richness of data, and when the data had reached the point of thematic saturation in addressing my research objectives. This was defined as data gathered until no new information was added; to the point of 'diminishing returns, when nothing new is being added' (Bowen, 2008). This was decided upon by reflecting on and reading earlier interview transcripts and meeting with data-collecting team members to iteratively discuss preliminary patterns and codes.

4.4.2 Participant observations

Participant observations were conducted by the researcher-observers between August 2018 and March 2019. Managers were asked to complete a questionnaire about their homecare agency [see Appendix 15], while homecare workers completed questionnaires to collect demographic information [see Appendix 16]. We collected each participating clients' care plan from the agency managers to provide context of the clients' care needs as well as their demographic information; we removed any identifiable information from the care plans. The agencies were reimbursed for any staff time taken to accommodate involvement in the participant observations, at a rate capped at £20 an hour.

I purposively allocated the homecare agencies within the researcher-observer team based on location and size. AB, JBD and I each independently observed homecare visits by two of the six homecare agencies. JBD carried out all observations with the two homecare agencies in the North of England, and AB and I each led observations with one London-based agency and one agency in the South of England (I observed the larger agencies that supported more clients living with dementia). Having one consistent researcher in each homecare agency facilitated rapport-building, whilst the written fieldnotes enabled ideas to be expressed between the observers as an

ongoing dialogue of both observations and reflexivity when working separately (Scales et al., 2011).

4.4.2.1 Familiarisation visits

The observation process began with up to two familiarisation visits where the researcher-observer accompanied the homecare worker as they provided support to their client living with dementia, without taking any fieldnotes. The purpose of this was for participants to become familiar with the researcher's presence before they began taking notes. The familiarisation period provided an opportunity to build rapport which is highlighted as a key methodological factor when carrying out ethnography with people living with dementia (MacLaren et al., 2017). These visits were also a chance for the researcher-observer to learn about the client and the homecare schedule. Contextual notes were typed-up after leaving the visit.

We (the researcher-observers) found the familiarisation period to be a very useful element to the observations, enabling participants to feel at ease when being watched by an outsider in the home. After the familiarisation visits, we checked with both the person living with dementia and homecare worker that they felt comfortable for the observations to begin at the next visit.

4.4.2.2 Observation visits

I designed a semi-structured observation plan to guide our observations [see Appendix 17]. Use of an observation plan aided consistency between the three researcher-observers and aimed to focus our fieldnotes in relation to my research objectives. The guide included two sections: 1) 'A practical overview of the visit'; prompting the researcher-observers to make notes on contextual information such as time, the home environment and tasks delivered, and 2) 'Interactions and responses of homecare workers with clients and others'. This section guided us to observe and make notes on where behaviours or interactions supported or challenged the client's independence (i.e. whether choice was offered, or how additional needs that arose were managed by the homecare worker). I also included a prompt for the researcher-observers to consider the impact of our presence when conducting observations. We kept reflective journals in addition to the fieldnotes.

We held weekly team meetings to iteratively discuss our observations and reflections. I led a reflective practice session with the wider NIDUS team in November 2018, as a half-way point for AB, JBD and I to share and discuss our observations with the wider research team. In this session, we considered our reflective stance as observers in the homecare setting and discussed similarities and differences in the homecare visits we each observed. The reflexive and analytic processes were therefore iterative and integrated.

During visits, the researcher-observers interacted conversationally with participants as felt natural, and I encouraged the use of an ethno-interview technique during the participant observations to enrich fieldnotes. These were informal and unstructured conversations with the homecare workers to gain a deeper understanding of what was being observed. In the literature, this type of interviewing is described as being akin to a 'casual conversation amongst acquaintances', which attempts to gain insight from the perspective of the observed (DeWalt & DeWalt, 2011). To carry out meaningful ethnography with people living with dementia, it was important to capture an 'understanding of how time, place and other activities and events may affect participants' (MacLaren et al., 2017, p. 7). Unstructured conversations with homecare workers both outside of and during visits were necessary to gain a full picture of the client from their knowledge of working with them. Where possible, we travelled with the homecare workers between client visits, where we were able to further discuss homecare provision without affecting their work.

All three researcher-observers wrote brief fieldnotes during observation visits. We sensitively considered when to make notes during observations. I was often standing or following the homecare worker around clients' homes, balancing my notebook on my arm. It often felt insensitive to take fieldnotes when engaged in conversation with the person living with dementia or family carer; at times I closed my notebook to signify that I was listening. AB and JBD reflected on similar experiences. We therefore took brief 'jottings' during homecare visits and wrote these up in full no more than 48-hours later to aid memory recall (Emerson, Fretz, & Shaw, 2011).

I also sketched my visual impressions of homecare situations, developing the sketches after the visits. This initially started as a time-saving approach, where I could create a rough sketch quicker than I could jot down notes. However, adding sketches into my observation fieldnotes quickly became a useful tool in translating my observations back to the research team, enhancing the iterative analytic process and also creating a visually accessible source of data when disseminating my findings to varied audiences. As posited by Heath and colleagues (2018) 'sketching can act as a bridge between researchers and non-researchers' (p.6). There is a growing interest in visual methods within contemporary science research (Prosser & Loxley, 2008) and observational sketching has strong roots within anthropological fieldwork (Kuschnir, 2016). Although less commonly than other forms of visual methods such as photography, drawing-based methods have been used in research as an elicitation tool with participants (Theron, Mitchell, & Smith, 2011) and as a tool adopted by researchers as a cognitive mapping exercise, as well as to aid memory, enhance visualisation of findings, and for dissemination (Heath et al., 2018).

4.4.2.3 Photo documentation

During the early stage of study recruitment, I noticed a striking contrast between two of the homecare agency offices I visited. I was curious about how these different environments might impact how homecare workers and agency staff interacted, both formally (i.e. in supervision or annual appraisal meetings) as well as informally (i.e. if homecare workers visited the office during breaks). I decided to ask the researcher-observers to photograph the office environments of all participating homecare agencies, in addition to written fieldnotes. Pink (2020) describes this as a 'hunch in visual ethnography' that 'involves the surfacing of not immediately obvious ways of doing, knowing and experiencing' (p.158) that we then hold on to throughout the fieldwork; without experiencing these things during fieldwork, we would never have known about them, or known to ask participants about (Pink, 2020).

Photography has been used as a key visual tool within ethnographic research to capture information (Watson & Till, 2010), as an elicitation tool to provoke further data (Johnson & Weller, 2002; Martin & Pilcher, 2018), to illustrate research findings (Collier, 1957), aid memory, increase clarity and minimise misunderstandings

amongst the research team (Harper, 2002). I obtained a substantial amendment to the study ethics approval to photograph the homecare agency offices. The researcher-observers took photographs on smart-phones and uploaded them onto a shared, protected team folder on a UCL or University of Bradford computer. The photographs were then deleted from the phones. The photographs did not contain images of people and any identifiable information that could compromise the anonymity of the homecare agency (i.e. logos or names on certificates) were pixelated. We did not take any photographs in clients' homes. Photographs are also useful for aiding the reflexive process, recording aspects of scenarios of interest, rather than scenarios as a whole, because the researcher's perspective of the images stem from the theory or hypothesis driving them (Pink, 2007). Prosser and Loxley (2008) argued that insufficient attention is given to visual representations of data, particularly when research is to be shared with audiences beyond academia.

4.5   Data analysis

4.5.1   Analytic approach

Being well suited to critical realist or post-positivist framings of data and meaning, I decided to use an inductive reflexive thematic analytic approach to analyse my data, based upon the guidance of Braun and Clarke (Braun & Clarke, 2006, 2013, 2019, 2020). I made this decision because of the theoretical flexibility of this approach and the 'fit' with my research questions and methods, interpreting the data from the reflective standpoints of the researchers; the researcher's role in knowledge production is a key dimension of this approach (Braun & Clarke, 2019).

In addition, I decided to use within-method triangulation (Denzin, 1970, 1978), integrating the data from the qualitative interviews and participant observations. Triangulation of data involves combining two or more data sources and is commonly applied to qualitative research (Flick, 2004); often to reduce bias and enhance validation across different methods of data collection (DeWalt & DeWalt, 2011). By triangulating different data sources, I also aimed to reveal different dimensions of a complex social phenomenon and achieve a more comprehensive and rich

understanding of the data, as is appropriate for qualitative data (Denzin, 2017; Mays & Pope, 2000).

4.5.2 Analytic procedure

I followed the guidance of Braun, Clarke and colleague's (Braun & Clarke, 2006, 2020; 2019) articulation of the 'six-phase process' for thematic analysis. This involved: 1) becoming familiarised with the data, 2) systematic coding of data, 3) generating initial themes from the coded data, 4) developing and reviewing themes, 5) refining and defining themes, and 6) producing the written report. The process of theme development was iterative, reflexive and collaborative with the wider research team, to enable a 'richer more nuanced' interpretation of the data (Braun & Clarke, 2019, p. 7).

I listened to the interview audio-recordings and checked the transcripts for accuracy, removing any identifiable information to preserve participant anonymity. I used NVivo 12 software (QSR International, 2018) to organise the data and began by reading all the interview transcripts and participant observation fieldnotes multiple times until I felt familiar with the data. I led the coding process. First, with two other researchers (HM and SGC), I developed codes from a random selection of 25% of interviews across participant groups, discussing our coding development iteratively. Then AB, JM, IA, PR, CC and I coded 15% of the observation fieldnotes, bringing in perspectives from psychology, psychiatry and social care backgrounds; AB, JBD and I coded our own fieldnotes first, taking our reflective notes into consideration whilst doing this, before another researcher second-coded to enhance inter-rater reliability; any discrepancies were explored and discussed amongst the research team.

The researcher-observers' reflective diaries were discussed during the regular reflective practice meetings and iteratively informed the coding process, particularly considering where the researcher-observers' presence might have impacted what was observed. I also attributed codes to all of the photographs and sketches and discussed these codes collaboratively with AB and JBD. I considered how the visual data situated in relation to the observation and interview data (Pink, 2020), exploring where it provided a nuanced or additional perspective (Martin & Pilcher, 2018).

Similar to the 'Following a thread' approach (Moran-Ellis et al., 2006), I compared the developed codes inductively from both datasets, exploring how codes from one dataset followed into the other until I developed one interwoven coding framework. I applied this framework thoroughly (in a line-by-line process) to the remaining interviews, half of the observation fieldnotes and all of the visual sketches and photographs, adding in any new codes until no new codes were found. I read the remaining fieldnotes in detail and compared them against the framework to ensure verification, comprehension and completeness of the data (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

In developing my themes, I created mind-maps to aid with visualising the data, and for idea-sharing with AB, JBD and my PhD supervisors. The use of mind-mapping is a technique used in rapid ethnographies to improve research accuracy and cross-check interpretations in real time (Vindrola-Padros, 2021a; Vindrola-Padros & Johnson, 2020). Considering my two research objectives, I then refined and defined my themes, also looking for divergences between the interview and participant observation data.

I discussed my preliminary themes with the NIDUS Community of Interest Group, presenting my initial findings and reflections on 6th October 2019 and again on 21st July 2020. The Community of Interest Group integrated involvement from people affected by dementia in the support of the wider NIDUS research programme. Members included two people living with dementia, family carers of people living with dementia, health and social care professionals, homecare staff and the wider NIDUS research team. The purpose of presenting my findings was to see how preliminary themes were interpreted and related to from the wider, more relevant viewpoint of key stakeholders involved in homecare for people living with dementia. This then aided with presenting the findings in the coproduction process of the NIDUS-Professional intervention (see Chapter 8).

4.6   Summary

In this chapter, I have described the methodology of my team-based ethnographic study, including the study design, ethical considerations, setting, participants and procedures, data collection and analysis.

In the next two chapters I will present the findings from this study in response to two of my research objectives:

Chapter 5: To learn and understand from the experiences of homecare workers how they can be better trained and supported in their role.

Chapter 6: To explore how homecare workers enable and/or inhibit independence at home for people living with dementia.

I will present the descriptive characteristics of the participants and homecare agencies at the start of Chapter 5.

In Chapter 7, I give a reflective account of my experiences as an ethnographic researcher.

Chapter 5   Skills, training and support needs of homecare workers

I begin this chapter by describing the socio-demographic characteristics of the participants in my ethnographic study, and the homecare agencies where the participant observations took place. I will then present the findings of my thematic analysis in response to my first objective, focusing on the skills, training and support needs of homecare workers who provide care to people living with dementia.

A paper from this analysis has been published in *Dementia: The International Journal of Social Research and Practice* [see Appendix 18].

5.1   Descriptive data

5.1.1   Qualitative interview study participants

In total, the research team interviewed 82 participants between March to August 2018: comprising 11 people living with dementia, 22 family carers, 19 health and social care professionals, and 30 homecare staff (7 managers, 4 office support staff and 19 homecare workers). This sample included 3 family carer-person living with dementia dyads, for whom family carers were interviewed separately. For 2 of these dyads, the family carer was also present when the person living with dementia was interviewed. Of the people living with dementia interview participants, the majority were White British (72.7%), with a mean age of 78.6 years; the sample was varied in terms of gender (male; 54.5%) and whether the person lived alone (45.5%) or with family/friends (54.5%).

The average age of family carer interview participants was 57.7 years, with variation in the sample regarding their relationship to the person living with dementia (i.e. spouse or adult child), ethnicity and marital status, with the small majority being retired (40.9%) or working part-time (22.7%); most of the family carers interviewed lived with the person living with dementia (77.3%; or the person lived with another relative/friend), as opposed to alone or in residential care.

There was much diversity in the job roles of the health and social care professionals interviewed, which included general practitioners, social/support workers, Local

Authority commissioners, amongst other roles. Most homecare staff interviewed were female (71.4% managers; 84.2% homecare workers and all of the office support staff) and White British (57.1% managers; 78.9% homecare workers and 75.0% office support staff); this is representative of the English homecare workforce and wider adult social care workforce (Skills for Care, 2019). Only 15.8% of homecare workers reported being employed on a zero-hour contract (compared to 56% of the workforce as reported by Skills for Care (2020a)), with 42.1% reporting working part-time, and 47.4% working full-time. Broader demographic information of interview participants is presented below (Table 5.1 for homecare staff; Table 5.2 for people living with dementia and family carers; Table 5.3 for health and social care professionals).

Table 5.1: Characteristics of homecare staff participating in interviews

Characteristic	Category	Agency managers (n=7)	Homecare workers (n=19)	Office support staff (n=4)
		n (%)/*mean (sd)*	n (%)/*mean (sd)*	n (%)/*mean (sd)*
Age		*49.6 (9.1)*	*48.9 (12.9)*	*43.3 (10.0)*
Gender	Female	5 (71.4)	16 (84.2)	4 (100.0)
	Male	2 (28.6)	3 (15.8)	0 (0.0)
Ethnicity	White British	4 (57.1)	15 (78.9)	3 (75.0)
	White Other	1 (14.3)	1 (5.3)	0 (0.0)
	Black/Black British Caribbean	1 (14.3)	1 (5.3)	0 (0.0)
	Black/Black British African	1 (14.3)	1 (5.3)	1 (25.0)
	Other	0 (0.0)	1 (5.3)	0 (0.0)
Contract	Zero hours	0 (0.0)	3 (15.8)	0 (0.0)
Employment	Working part time	0 (0.0)	8 (42.1)	1 (25.0)
	Working full time	7 (100.0)	9 (47.4)	3 (75.0)
	Other	0 (0.0)	2 (10.5)	0 (0.0)
Years worked in social care	6 months – 1 year	0 (0.0)	3 (15.8)	0 (0.0)
	1 – 3 years	1 (14.3)	2 (10.5)	0 (0.0)
	3 – 5 years	0 (0.0)	4 (21.1)	0 (0.0)
	5 – 10 years	1 (14.3)	5 (26.3)	1 (25.0)
	More than 10 years	5 (71.4)	5 (26.3)	3 (75.0)
Years worked in current agency	Less than 6 months	0 (0.0)	2 (10.5)[a]	0 (0.0)
	6 months – 1 year	0 (0.0)	4 (21.1)	1 (25.0)
	1 – 3 years	1 (14.3)	5 (26.3)	1 (25.0)
	3 – 5 years	0 (0.0)	3 (15.8)	0 (0.0)
	5 – 10 years	4 (57.1)	3 (15.8)	1 (25.0)
	More than 10 years	2 (28.6)	1 (5.3)	1 (25.0)
Personal experience of dementia	Yes	5 (71.4)	9 (47.4)	1 (25.0)

[a] One homecare worker was unable to specify number of years worked in current agency

Table 5.2: Characteristics of people living with dementia and family carer interview participants

Characteristics	Category	People living with dementia (n=11)	Family carers (n=22)
		n (%)/*mean (sd)*	n (%)/*mean (sd)*
Age [a]		*78.6 (7.8)*	*57.7 (14.3)*
Gender	Female	5 (45.5)	12 (54.5)
	Male	6 (54.5)	10 (45.5)
Ethnicity	White British	8 (72.7)	9 (40.9)
	White Other	1 (9.1)	0 (0.0)
	Black/Black British Caribbean	0 (0.0)	0 (0.0)
	Black/Black British African	0 (0.0)	0 (0.0)
	Asian/Asian British Indian	0 (0.0)	6 (27.3)
	Asian/Asian British Bangladeshi	0 (0.0)	4 (18.2)
	Other	2 (18.2)	3 (13.6)
Marital status	Single	3 (27.3)	5 (22.7)
	Married	4 (36.4)	11 (50.0)
	Divorced	1 (9.1)	3 (13.6)
	Widowed	3 (27.3)	1 (4.5)
	Other	0 (0.0)	1 (4.5)
Education	Primary (up to age 11 or 12)	1 (9.1)	1 (4.5)
	Secondary (up to GCSE)	7 (63.7)	4 (18.2)
	Further (AS/A-level, NVQ, Diploma)	1 (9.1)	6 (27.3)
	Degree	1 (9.1)	4 (18.2)
	Postgraduate	1 (9.1)	7 (31.8)
Employment	Working part time	0 (0.0)	5 (22.7)
	Working full time	0 (0.0)	2 (9.1)
	Retired	10 (90.1)	9 (40.9)
	Unemployed	1 (9.1)	3 (13.6)
	Other	0 (0.0)	3 (13.6)
Relationship to person living with dementia	Spouse/partner	-	6 (27.3)
	Son	-	8 (36.4)
	Daughter	-	4 (18.2)
	Niece/Nephew	-	2 (9.1)
	Sibling	-	1 (4.5)
	Friend	-	1 (4.5)
Living situation of person living with dementia	Lives alone	5 (45.5)	2 (9.1)
	Lives with family/friends	6 (54.5)	17 (77.3)
	Lives in care home (previously lived at home)	0 (0.0)	3 (13.6)
Years since dementia diagnosis [b]	Less than 6 months	1 (9.1)	0 (0.0)

	6 months – 1 year	0 (0.0)	0 (0.0)
	1 – 3 years	4 (36.4)	9 (40.9)
	3 – 5 years	2 (18.2)	4 (18.2)
	5 – 10 years	1 (9.1)	1 (4.5)
	More than 10 years	0 (0.0)	1 (4.5)
	Unable to specify	3 (27.3)	2 (9.1)
Type of dementia [c]	Alzheimer's disease	3 (27.3)	8 (36.4)
	Vascular	2 (18.2)	4 (18.2)
	Mixed	1 (9.1)	1 (4.5)
	Other	1 (9.1)	2 (9.1)
	Unable to specify	4 (36.4)	2 (9.1)

[a] One person living with dementia and one family carer did not report their age

[b] Five family carers did not report when the person living with dementia received a dementia diagnosis

[c] Five family carers did not report the type of dementia the person living with dementia was diagnosed with

Table 5.3: Characteristics of health and social care professional interview participants

Characteristics	Category	Health & Social Care Professionals (n=19)
		n (%)/*mean (sd)*
Age [a]		*41.4 (10.94)*
Gender	Female	13 (68.4)
	Male	6 (31.6)
Ethnicity	White British	9 (47.4)
	White Other	5 (26.3)
	Black/Black British Caribbean	0 (0.0)
	Black/Black British African	0 (0.0)
	Black/Black British Other	1 (5.3)
	Asian/Asian British Indian	2 (10.5)
	Asian/Asian British Bangladeshi	0 (0.0)
	Other	2 (10.5)
Role	GP/Assistant practitioner	4 (21.1)
	Psychiatrist	1 (5.3)
	Psychologist	2 (10.5)
	Physiotherapist	1 (5.3)
	Social worker/Support worker	3 (15.8)
	Commissioner (Local Authority)	3 (15.8)
	Service Lead/Team Manager (NHS)	2 (10.5)
	Service Lead/Team Manager (Local Authority)	2 (10.5)
	Community Mental Health Nurse	1 (5.3)
Years worked in dementia care	6 months – 1 year	0 (0.0)
	1 – 3 years	1 (5.3)
	3 – 5 years	5 (26.3)
	5- 10 years	5 (26.3)
	More than 10 years	8 (42.1)
Years worked in current role	6 months – 1 year	2 (10.5)
	1 – 3 years	2 (10.5)
	3 – 5 years	5 (26.3)
	5 – 10 years	5 (26.3)
	More than 10 years	5 (26.3)
Personal experience of dementia in family/friend	Yes	12 (63.2)
	No	7 (36.8)
[a] One health and social care staff participant chose not to disclose their age		

5.1.2   Participant observations - homecare agencies

Between September 2018 and March 2019, we (AB, JBD and I) observed homecare provided by six commercial agencies. I purposively selected these agencies to include diversity in agency location, size and client funding (Local Authority and private). Two agencies were based in London, two in the South of England and two in the North of England. Two agencies provided care to privately funded clients only, one solely supported clients whose care was paid for by their Local Authority, and three cared for clients whose care was funded by either of these payment routes. Care Quality Commission (CQC) inspections, at the point the agencies joined the study, rated five of the agencies 'Good' and one as 'Outstanding'. At the start of the observation study, one of the agencies underwent a routine CQC inspection and their rating was downgraded from 'Good' to 'Requires improvement'. The characteristics of the homecare agencies are displayed in Table 5.4.

Table 5.4: Characteristics of homecare agencies participating in observations

Homecare agency (n=6)	Location	Care Quality Commission (CQC) rating	Total number of clients (% of clients with dementia or memory problem)	Homecare workers on a zero-hour contract (% of all employed)	Client funding	Homecare workers observed	Clients with dementia observed
1	London	Good	91 (39.5)	85 (100.0)	Private	1	1
2	London	Good	150 (4.6)	90 (100.0)	Local authority	2	2
3	South England	Good	28 (53.6)	1 (6.6)	Private	3	2
4	South England	Good [a]	180 (45.0)	67 (95.7)	Private & local authority	5	7
5	North England	Outstanding	112 (62.5)	74 (93.7)	Private & local authority	3	3
6	North England	Good	196 (31.6)	120 (95.2)	Private & local authority	2	2

[a] CQC rating changed from 'Good' to 'Requires Improvement' at the start of the observation period

5.1.3   Participant observations: Participants

Across the six agencies, 16 homecare workers were observed providing care to 17 clients living with dementia. Four homecare workers took part in both the qualitative interviews and participant observations. Twenty-one homecare workers consented to be observed. Three left the study prior to familiarisation visits (due to illness, client declining participation, and overlap in the researcher-observer's schedule respectively). Two homecare workers did not participate following one familiarisation visit, due to illness and not having regular visits scheduled with a client, respectively. Two people living with dementia from one agency consented to observations but did not take part. For one person, this was due to overlap with the researcher-observer's schedule and for the second person, the research team made an in-situ decision to cease observations within that particular agency, as our sampling target had been met (Braun et al., 2019); five clients had been observed receiving care from the same homecare worker. Two people living with dementia were observed during familiarisation visits only, due to subsequent hospitalisation. Recruitment and retention of homecare workers in the study are displayed in Figure 5.1 and of people living with dementia in Figure 5.2.

Over 100 hours, we observed 104 homecare visits (including 26 familiarisation visits), with additional observations within agencies' offices and during travel. Using pseudonyms, I have outlined in Table 5.5, which homecare workers were observed providing care to which clients living with dementia, and where overlap occurred. For example, in some observations, more than one homecare worker provided care for the same client (either alone or as a 'joint visit' with another homecare worker), and some homecare workers were observed supporting more than one client.

People living with dementia observed had an average age of 86 years. The majority were female (82.4%), living alone (64.7%) and in receipt of Local Authority funded homecare (64.7%). Ethnicity of participants was reported as White British (76.5%), British (11.7%) and Black Caribbean (5.9%); ethnicity was not reported for one person living with dementia. The characteristics of the participants living with dementia observed are presented in Table 5.6. Homecare workers observed were all female

and predominantly White British (75.0%), with an average age of 49 years. Only five (31.2%) homecare workers reported being employed on a zero-hour contract; this does not reflect the proportion of staff on zero-hour contracts stated by participating homecare managers (see Table 5.4). Broader demographic information of the homecare workers observed is displayed in Table 5.7.
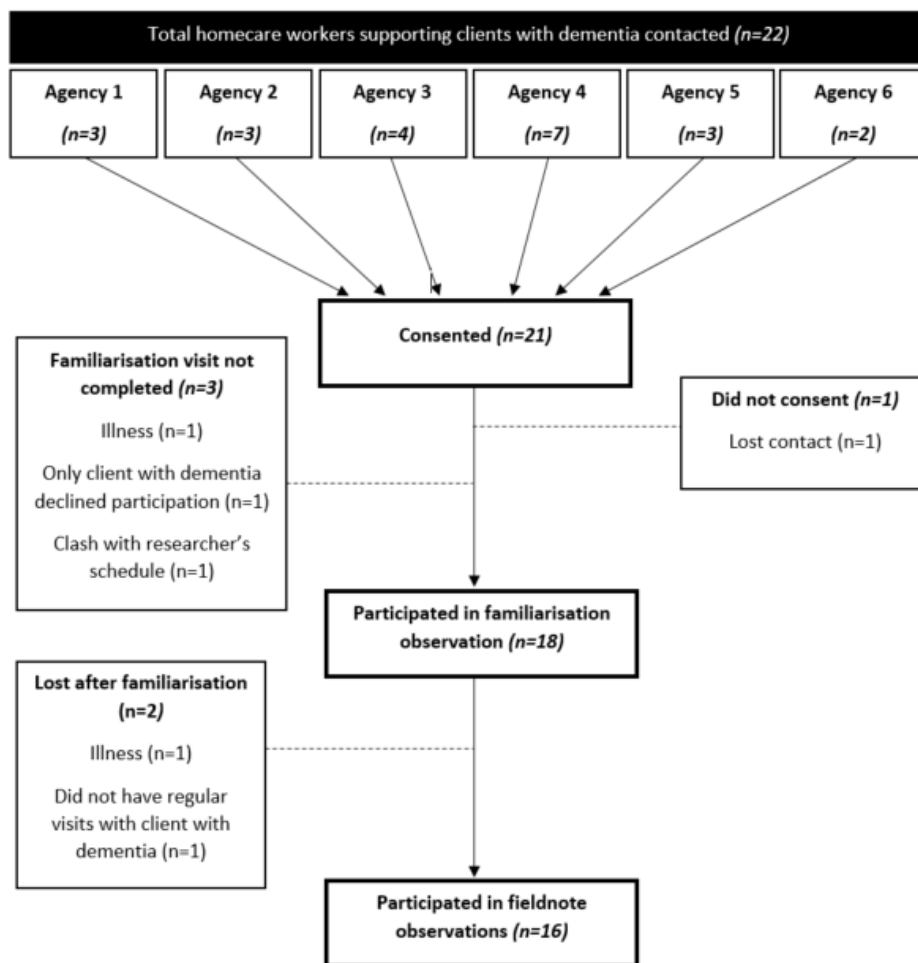
Figure 5.1: Participant observations - recruitment and retention of homecare workers
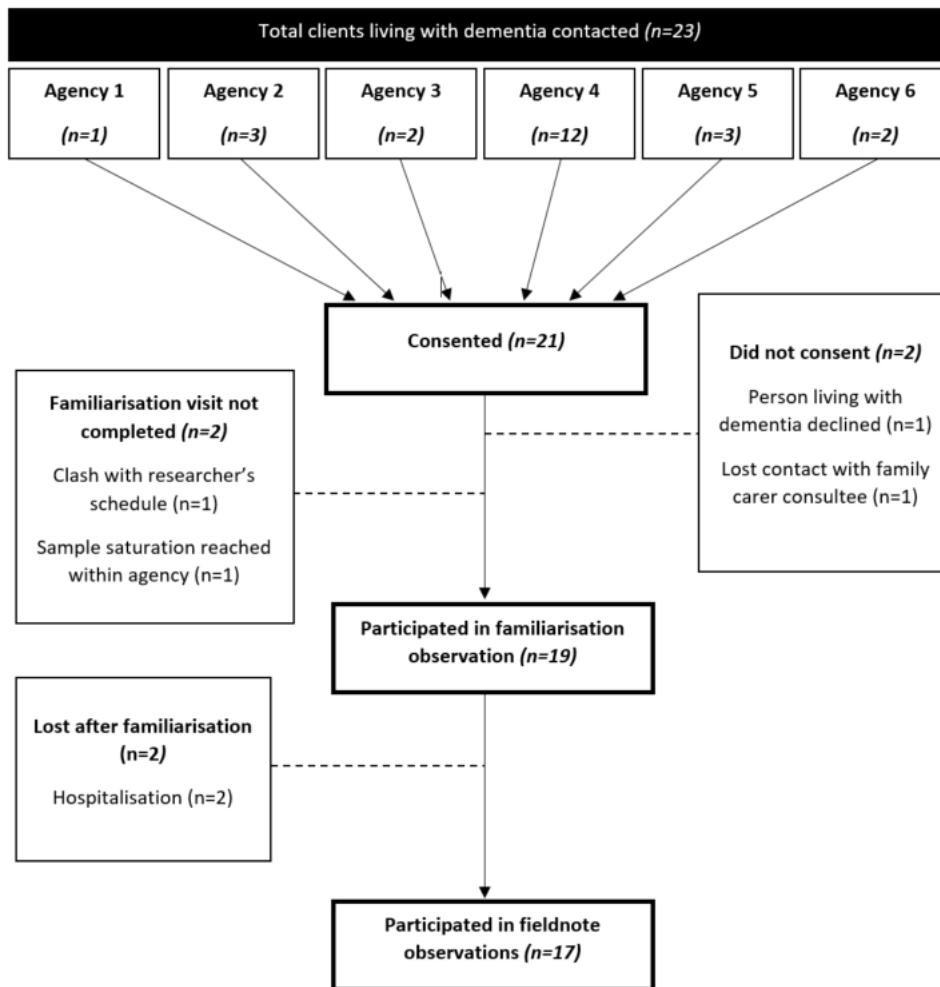
Figure 5.2: Participant observations - recruitment and retention of people living with dementia

Table 5.5: Mapping homecare workers to the clients they supported

Agency	Homecare worker	Client living with dementia	Joint visits
1	Angela	Betty	No
2	Anya	Belinda	No
	Avery	Barbara	No
3	Alina	Beverly [a]	Yes
	Abbey		
	Ashley		
		Bonnie	No
4	Audrey	Beatrice	No
	Anna		No
	April	Brian	No
		Beth [b]	Yes (for personal care visits)
	Amy		
	Alison		
		Bernice	No
		Bridgette	No
		Brenda	No
		Benji	No
5	Aida	Bara	No
	Alexa		No
		Boris	No
	Annie	Benita	No
6	Amanda	Bryony	No
	Aysha	Bea	No

[a] All of Beverly's observed homecare visits were provided by three homecare workers who were consistently scheduled to support Beverly. They were observed providing care together in different paired rotations.
[b] Beth's personal care visits were scheduled with two homecare workers. There were often last-minute staffing changes and the second homecare worker was usually a different person to the previous visit.

Table 5.6: Characteristics of people living with dementia observed receiving homecare

Pseudonym	Age	Sex	Ethnicity	Living situation	Capacity to consent	Care funding	Homecare workers observed (n)	Scheduled visit duration	Requires support with (as stated in the care plan)
Betty	*Missing data*	Female	White British	Lives alone	Yes	Private	1	3-hours	Medication management, meal preparation, prompt washing and support with dressing, domestic support, arranging and accessing appointments in the community, food shopping
Beverly	77	Female	White British	Lives with spouse	No	Private	3 (2 homecare workers at each visit)	1-hour	All support delivered in bed: Personal care, dressing, companionship, domestic support
Bonnie	84	Female	White British	Lives alone	Yes	Private	1	1.5–3 hours	Personal care, meal preparation, medication management, domestic support, accessing the community
Belinda	82	Female	Black Caribbean	Lives alone	No	Local authority	1	30-minutes	Meal preparation, meal-time companionship, medication management
Barbara	80	Female	White British	Lives with son	No	Local authority	1	30–45 minutes	Getting out of bed, personal care, meal preparation, companionship, medication management
Brian	61	Male	White British	Lives with spouse	No	Local authority	1	3-hours (sitting service)	Respite for family carer, meal preparation, personal care
Beth	85	Female	White British	Lives with spouse	No	Local authority	3 (2 homecare workers for personal care visits)	15–30 minutes + 4-hour respite	All support delivered in bed: Personal care, reposition and assess pressure areas, transfer using hoist, respite for family carer

Name	Age	Gender	Ethnicity	Living		Funding		Duration	Care needs
								visits twice weekly	
Beatrice	96	Female	White British	Lives alone	No	Local authority	2	3-hour shifts; 24-hour care package	All personal care needs require support
Brenda	93	Female	White British	Lives alone	Yes	Local authority	1	30-minutes	Meal preparation
Benji	84	Male	White British	Lives with spouse	No	Local authority	1	30-minutes	Personal care, support with dressing, medication management
Bernice	89	Female	White British	Lives alone	Yes	Local authority	1	15-minutes	Meal preparation, medication management
Bridgette	94	Female	White British	Lives alone	Yes	Local authority	1	30-minutes	Meal preparation, medication management, domestic support
Boris	77	Male	British	Lives with spouse	No	Private	1	2-hours	Personal care, meal preparation, companionship, mental stimulation, mobility support around home
Bara	98	Female	*Missing data*	Lives alone	No	Private	2	1-hour	Personal care, support with dressing, meal preparation, administering medication, domestic support
Benita	88	Female	British	Lives alone	No	Private	1	1–5 hours	Domestic support, companionship, accessing the community, arranging appointments, food shopping, pet care
Bryony	99	Female	White British	Lives alone	No	Local authority	1	30-minutes	Personal care, dressing, meal preparation, medication management, domestic support
Bea	89	Female	White British	Lives alone	No	Local authority	1	30-minutes	Meal preparation, medication management, domestic support, companionship

Table 5.7: Characteristics of homecare workers participating in observations

Characteristic	Category	Homecare workers (n=16)
		n (%)/*mean (sd)*
Age [a]		*49 (5)*
Gender	Female	17 (100.0)
Ethnicity	White British	12 (75.0)
	White Other	1 (6.3)
	Black/Black British Caribbean	1 (6.3)
	Black/Black British African	2 (12.5)
Contract	Zero hours	5 (31.2)
Employment	Working part time	5 (31.2)
	Working full time	11 (68.8)
Years worked in social care	6 months – 1 year	3 (18.8)
	1 – 3 years	4 (25.0)
	3 – 5 years	1 (6.3)
	5 – 10 years	4 (25.0)
	More than 10 years	4 (25.0)
Years worked in current agency [b]	Less than 6 months	1 (6.3)
	6 months – 1 year	3 (18.8)
	1 – 3 years	7 (43.8)
	3 – 5 years	2 (12.5)
	5 – 10 years	2 (12.5)
Personal experience of dementia	Yes	6 (37.5)
[a] Three homecare workers did not report their age [b] One homecare worker was unable to specify number of years worked in current agency		

5.2   Qualitative analysis

In response to my research question exploring the skills, training and support needs of homecare workers, I identified four themes. These were: 1) 'Navigating the homecare identity and role', 2) 'Developing and utilising relational and emotional skills', 3) 'Managing risk, resistance and behaviours that challenge', and 4) 'Drawing on agency and team support'. All themes drew on both methods of data collection. While I did not have an *a priori* intention to give greater weight to either data source, the balance between them varied by stakeholder group. Interviews were the primary source of data for non-frontline professionals (e.g. homecare managers) who were not usually present in observations, and for family carers. Experiences of people living with dementia were gleaned mostly from observations, which allowed perspectives to be conveyed, verbally and non-verbally in-the-moment, circumventing memory loss; albeit interpreted by the research-observer. Observations also captured interactions between participants. Interviews and observations seemed to contribute equally to my findings regarding homecare worker perspectives. All participant groups identified challenges of homecare for people living with dementia and plausible solutions to embed into homecare workers' training and support. Some solutions suggested were beyond the scope of training, as they would require organisational or policy changes, for example to funding or scheduling arrangements.

To aid comparison, supporting interview quotes will be presented in blue and observation fieldnotes in green. I have used anonymised identifiers for interview participants and pseudonyms throughout fieldnotes to protect the identity of participants: 'A' names for homecare workers, 'B' names for people living with dementia, and 'C' names for family carers.

5.2.1   Theme one: Navigating the homecare role and identity

In this theme, I explore an ambiguity I identified across stakeholders around the role of homecare workers, including with regards to its boundaries and limits. I will outline the different role identities held by homecare workers in the first subtheme, and in the second subtheme I consider the expectations and tensions between homecare

workers and clients living with dementia, their family carers and sometimes health and social care professionals that appeared to arise from those identities.

5.2.1.1   Subtheme A: Role Identity

In this sub-theme, I reflect on the different identities that homecare workers adopted, often in parallel including: the proxy healthcare professional, a companion to clients and their family members, and a home-help. As a proxy-care professional, homecare workers were positioned to carry out health-related tasks, such as caring for a client's wounds, often in our observations, without the training to do so. As a companion, there was a sense of reciprocity, including homecare workers' learning what to do 'on the job' together with the client and their family members. As the home-help, homecare workers were guided by the client's care plan and carried out domestic tasks the client was no longer able to do.

<u>The proxy-care professional</u>

The homecare role was described and observed as needing the skills traditionally associated with health and social care professionals. Such roles included a counsellor, providing support and advice to both the clients and their family members; a nurse, taking on tasks to help manage clients' physical health needs; or a warden, responsible for their clients' safety and wellbeing. We observed situations where clients' homecare overlapped with health and social care visits, which often involved the care professional positioning the homecare worker as a proxy, to carry out tasks in their absence. There were elements to which the homecare worker was positioned as proxy for the professional, and perhaps also a degree to which they were a proxy for the client, who if they were able to do so, may have been instructed in self-care. For example, one homecare worker was instructed by a district nurse to care for a client's wounds, upon returning from a short stay in hospital following a fall:

'Bridgette was still wearing the hospital bracelet. The district nurse told Alison how to care for Bridgette's wounds, redressing with the bandages and not pulling out the stitches as they will dissolve. Alison didn't ask any questions and nodded along saying yes as the nurse spoke to her.'

In other examples, homecare workers reiterated the advice given by professionals, to remind and encourage their clients living with dementia to complete necessary tasks, such as how to prevent infections:

'Angela reminds Betty that the doctor has told her she must stop using soap to wash her private areas as the soap has been causing her infections. Betty agrees and repeats what she remembers of this correctly, and then drains the sink to remove the soap from the water.' (Agency 1)

'Audrey says she has taken advice from the district nurse recently as Beatrice has been getting water infections so needs to drink more. Beatrice is encouraged when Audrey tells her the nurse has advised something. Audrey thinks this relates back to Beatrice having been a nurse herself.' (Agency 4)

As in these examples, homecare workers were observed directly seeking advice from the clients' healthcare professional. This seemed to provide homecare workers with reassurance of giving correct advice to their clients, as well as instilling greater confidence in their clients living with dementia. In the above example, Beatrice seemed more reassured when informed the advice had come from her nurse.

Homecare workers were sometimes uncertain of the extent to which supporting clients with their healthcare fell within the remit of their role. This was particularly evident around supporting clients to take prescribed medication:

'Ashley asks Abbey if they should put in eye drops as Beverly's eye looks sore. Abbey says that they cannot issue medication.' (Agency 3)

Some family carers and care professionals felt that homecare workers lacked knowledge or confidence in their ability to carry out certain healthcare tasks, such as changing stoma bags, without sufficient training. In one observation, the researcher-observer raised a safety concern regarding how the client's medication had been administered by the homecare workers:

'Alexa sets the small patterned tray with a knife and fork and uses a tea spoon to get the tablets out of the dossette and into the usual egg cup to dispense them - in

doing so one of the tablets flicks onto the kitchen floor. Alexa pauses and then says out loud "I should get rid of that, shouldn't I?". This sounds like a rhetorical question – after another pause Alexa puts the tablet in the bin and tells me that last week another homecare worker had found some medication that had been dropped by the client in her chair so she does not think missing one tablet will be a problem.' (Agency 5)

In this example, the homecare worker lacked knowledge around medication management and risk to understand the safety issues around these incidents. However as in the example below, with the appropriate training homecare workers were perceived to be well situated to carry out tasks relating to the client's health care:

'So actually having people like occupational therapist people or stoma nurses being able to come into a situation, train the carer team supervisor who will cascade that information and say, here you go, you guys can do this now... it would make a world of difference.' (Family Carer 19)

In the above quote, the family carer hoped that homecare workers would have clinical skills and thus act as a proxy clinical professional. This role is one often taken on by family carers too, to substitute for self-care when the care recipient cannot do so, but the family carer in the quote above had expectations that the homecare worker's role was more aligned with a clinical professional.

Narratives from homecare managers drew distinctions between health and social care professionals and homecare workers, perceiving that the homecare role was undervalued, and its importance unrecognised. In the example below, a homecare manager reflected on the value of homecare workers' familiarity and understanding of their clients, in addition to their training and experience, which should situate them as valued contributors to the healthcare multidisciplinary team:

'...Yes, they are not as highly qualified as a district nurse, or an occupational therapist, but they have training, and they are in there seeing the client every day.

<u>The personal companion</u>

Homecare workers were valued by clients and family members as companions, friends or likened to a family member. Homecare workers in turn considered building positive relationships as essential to good care provision and a cherished part of the job, using terms such as 'aunty' or 'good friend' to describe their clients. Discourses around the homecare worker as a companion contrasted with professional discourses, giving rise to a different set of rules, relationships and interactions. They suggested a sense of reciprocity and also an equivalence of status with clients and family carers, such as in the examples below where the homecare workers were perceived to learn and work together with the client living with dementia and family carer:

'Angela says her and Betty "work like each other's brains".' (Agency 1)

'Clara describes Alison as an 'angel' and a 'God-send', saying that she is like a daughter to her and Benji. She tells me that Alison was the first homecare worker that Benji had and Alison had also just started being a homecare worker, so they learned what to do together.' (Agency 4)

The quote above implies that some skills are not taught but evolve throughout the course of the relationship with the client and their family.

The identity of personal companion, and the consequent framing of client relationships as being equal in status, seemed to be reassuring to clients and family members. Yet, the quote above suggests that at times this intentional or unintentional framing risked diminishing the skills and identity of the homecare worker as a trained professional.

Another result of this relational positioning was that professional boundaries could blur. In some cases, the sense of being part of the inner familial system led to certain homecare workers passing judgements on less-involved or distanced family

members, who they perceived as not doing enough for the person living with dementia:

'Betty says Cliff [long-distance family member] is a nice man who seems happy to keep her affairs in order. This is contrary to what Angela had told me, that Cliff "didn't bother" with Betty and hadn't seen her for the past 4-months.' (Agency 1)

There were also examples where homecare workers became involved in activities beyond the remit of the homecare role. One homecare worker reported in the interview that she had agreed to be the witness for her client when signing her will, in place of the client's family members:

'And then I went in the next day, [she] looked anxious again and I said, "what are you worrying about?". She said, "I don't want my children here when I write the will". So, I had to ring the daughter and son and tell them that she wants me to be there, and I actually witnessed her will.' (Homecare Worker 12)

A home-help

Homecare workers also provided domestic support, substituting for aspects of life the client could no longer do. These were often the tasks that homecare workers spent the most time engaged in. They included supporting the client living with dementia with cooking, gardening, home maintenance, and sometimes, pet care:

'And you do have to do everything, from personal care to medication to gardening to cooking. You really are, you're sort of being the eyes and the ears and the hands of that person.' (Homecare Manager 3)

'Observed tasks during today's visit included: Annie taking Benita's dog for a walk, putting eye cream on the dog and making arrangements with Benita's neighbour for dog care over the weekend.' (Agency 5)

This identity was most clear-cut for homecare workers, as domestic tasks were outlined in the clients' care plan. However, challenges arose when balancing these

tasks with the needs and wants of clients and their family members, as I discuss in the next subtheme.

5.2.1.2 Subtheme B: Role expectations and boundaries

In this sub-theme, I explore how role ambiguity gave rise to tensions amongst all participant groups. Homecare workers faced dilemmas when stakeholders had different expectations of their role, and in turn, clients living with dementia and their family carers could feel that their individual needs were not being met by their homecare support. For example, one client living with dementia expressed frustration when homecare workers seemed too focused on completing the care plan's set tasks, rather than talking to them during the visit:

'…give more time for the people, rather than the doing… It then gives the [homecare worker] the time to ask the person how they are, instead of fussing around doing the practical things; they can actually talk to the person then.'
(Person Living with Dementia 17)

Completing care plan activities in the time available could be challenging for homecare workers and even small additional requests could feel burdensome:

'Brenda asks if she can have some gravy with her dinner… Alison leaves the bedroom and mutters "what is it with everyone and gravy today?". Her tone is frustrated as she refers to the previous client who also asked for gravy with her dinner just as Alison was preparing to leave.' (Agency 4)

Balancing the care plan with the client and their family carers' wishes and expectations tested homecare workers' professional boundaries. We observed numerous occasions where they were asked to do tasks beyond their remit or outside scheduled visit times. In one observation, a family carer asked a homecare worker to monitor the client via an online camera, beyond her working hours:

'Angela shows me the motion-sensored camera in Betty's bedroom that Cliff had asked her to monitor. The camera is connected to an app on Angela's phone which

she often checks to see that Betty is safe when she is alone. Angela says that if she saw anything was wrong she would be the first to rush over.' (Agency 1)

Being asked to take on such a position could bring rewards of esteem and satisfaction from being trusted and autonomous, but also anxieties at levels of responsibility that could be excessive or intrusive; Angela reported 'not being able to switch off' from her role, with other homecare workers describing a weight of responsibility. Some homecare workers were more cautious of the repercussions of taking on responsibility beyond their role, recognising the vulnerability in their role to receive blame or be accused of negligence, if something went wrong. As discussed in the example below, closely following the homecare agencies' policies and procedures provided protection against such risks:

'I get on well with her [the client's wife], it's just when she wants to have things her own way, and I know that it's not the right way, rather… It's the policies, the procedure that has to be followed… we have to abide by the rules.' (Homecare Worker 13)

Homecare workers' competency or value could be questioned if they did not meet stakeholders' expectations. Some family carers described homecare workers as not doing their job if they did not agree to additional requests outside of the client's care plan. One family carer voiced frustrations when the homecare worker would not clean the carpets in her relative's home:

'Getting these carers [in] and I'm being reacquainted with the limitations of social services care workers who all say, "I'm sorry, I don't do that" …. They wouldn't clean her carpet, so I had to do that.' (Family Carer 11)

Being unable to meet additional requests of clients living with dementia and their family carers was often a consequence of limited time, and therefore funding. Some homecare workers reported asking for advice or support from their manager to navigate such situations without disappointing clients or their family carers. This was sometimes resolved by updating the clients' care plan to reflect additional needs and requesting longer visit times when supporting certain clients.

5.2.2 Theme two: Developing and utilising relational and emotional skills

In this theme, I explore the close and complex relationships that often developed between homecare workers and clients living with dementia, and their family carers, as well as what supported and enabled these relationships. In the first subtheme, I present the relational and emotional skills that were important for homecare workers to develop when building rapport with clients living with dementia, such as empathy, and the importance of consistent scheduling to enable homecare workers to get to know their clients and family carers. In the second subtheme, I consider how homecare workers managed these relationships, including the associated challenges of forming emotional attachments to clients and their family carers.

5.2.2.1 Subtheme A: Building relationships with clients living with dementia and their family carers

In this subtheme, I drew upon the shared understanding across all participant groups that 'getting to know' and becoming familiar with clients and their families was critical to good homecare for people living with dementia. The skills required included the ability to communicate and form an understanding of the client living with dementia. This was described as 'getting to know the person… what the person likes or doesn't like, what the person can do, what they can't do.' (Family Carer 22) and the need to 'talk the same language' (Homecare Worker 23), both figuratively and literally.

Valuing and respecting the client as 'a person with dementia… they're not dementia' (Homecare Worker 12), or in other words, being able to see the client beyond their dementia diagnosis, was a skill perceived as imperative to developing positive relationships. One homecare worker described utilising skills of empathy when delivering care to her clients living with dementia:

'You bond, you're going into the most vulnerable, you've gone in when the dignity has gone, they are relying on you to take them to the toilet. You've got to remember that that could be me one day, and you've got to say to yourself this is how I'd want to be treated or this is how I want my dad to be treated.' (Homecare Worker 12)

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Beyond the individual skills of homecare workers, some homecare agencies strove to facilitate positive relationship building by matching homecare workers with clients living with dementia. The process of matching could be based on age, similar interests, social and cultural values, or the homecare workers' experience or skill level with the clients' level of need:

'That's the good thing about [Home Care Agency] … they do make the effort of matching a carer with a client. And if it doesn't work either way round, they listen and they do something about it, because that is so important… nobody likes to think you're not going to get on with somebody, but it happens, clash of personality or whatever.' (Homecare Worker 24)

In one example, we heard about a family carer discontinuing their support when the homecare worker's care provision was perceived to not align with the client's culture; this became particularly evident around meal preparation:

'The thing is, because she likes a certain way of cooking, a certain type of food, she didn't want someone, you know, a Caucasian female coming in and making like a vegetable stew with water and some salt, and then here you are Madam. It's not her cup of tea… So, it's very difficult. She basically refused their assistance.' (Family Carer 13)

Developing relationships of familiarity often relied on consistent visit scheduling. Regularly seeing new faces was difficult for people living with dementia, whilst consistency could enable mutually enjoyable bonds to form. Figure 5.3 portrays a regular scene between a homecare worker (Angela) and her client living with dementia (Betty); through continuous care scheduled five-days per week over a two-year period, the dyad had established a number of mutually enjoyed comic routines, particularly during personal care tasks. As in the scene below, Betty made purring sounds mimicking a cat, whilst Angela applied a medically prescribed cream to her legs:

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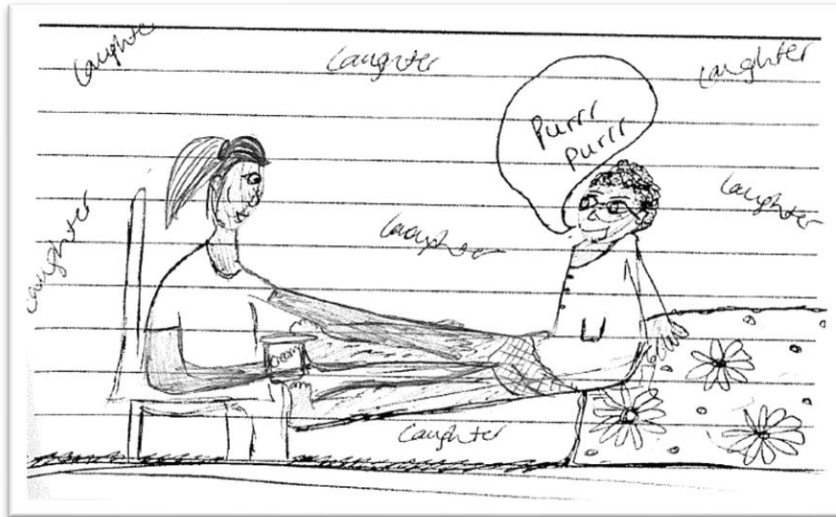
Figure 5.3: Observation sketch of a familiar routine between Angela and Betty

Relationships that developed between homecare workers, their clients and family carers were not always positive. One homecare worker, Alison, who I observed providing care to five clients in total, reported feelings of anxiety before visiting one particular client each week. Alison told me the client 'didn't like her' and described her as being verbally abusive, giving several examples where the client shouted at her or complained about her work:

'She told me that Brenda had been "nasty" to her and felt she didn't deserve the abuse as she was just doing what she was told to. I probed about this further and Alison said that Brenda had shouted at her for giving her dinner too early and called the food "slop".' (Agency 4)

This behaviour was not observed during the observations however, and Alison described the client as being more 'tolerable' while I had been present during the visits (discussed further in Chapter 7: Reflections as an ethnographic researcher). Alison had reported this to the agency manager, and at times had 'refused' to provide care to the client; although this case was not reallocated in the time of the study. Alison perceived herself to be the problem as 'Brenda likes all the other carers' (Agency 4); this sense of personal rejection was likely associated with Alison's approach to managing the situation, by getting in and out of the visit as quickly as

possible 'to just get it over with'. However, this often led to Alison leaving the visit early and the client living with dementia receiving rushed care:

'Alison seems to be in a rush to leave Brenda's bedroom [where Brenda is lying in bed], to go into the kitchen. As she does this, Brenda is still talking to her but Alison can no longer hear from the kitchen. Brenda calls out louder to ask Alison if she had given her three tablets. Alison calls out "yes" from the kitchen but Brenda calls back to say she cannot hear her. Alison rolls her eyes.' (Agency 4)

This was in contrast to reports from homecare workers and managers in interviews, who described a policy of reassigning a different homecare worker if either the homecare worker or client was unhappy with the existing relationship. Developing positive relationships with clients living with dementia was heralded as central to the role and something to strive towards, which could lead to homecare workers feeling they had failed in their role if this was not achieved.

Homecare workers also found it challenging when there was not a clear pathway for communication with their clients' family carers, particularly when they identified problems that required intervention from the family. In these situations, homecare workers typically reported the problem to agency office staff, who would pass the information on to the client's family. However, a lack of direct communication between homecare workers and family carers could lead to delays in addressing the issues, or could create negative attitudes between the two participant groups. In the example below, a homecare worker described a situation where her client had run out of food, but perceived that the family carers were unhappy when told about this by the agency staff:

'Aysha discusses that in the past she has fed back to the office about the client having no food… she had made the client beans on toast for four days. This was passed back to the family and she thinks the family were not happy. She says that sometimes the family say that they will do something and then don't.' (Agency 6)

Aysha also discussed having considered escalating her concerns regarding the state of the client's home to social services, but the family carers eventually sorted out the

issues. Aysha showed the researcher-observer that the client's carpets had recently been replaced, as evidence of the family taking action after she had raised concerns about the client's risk of falls.

5.2.2.2 Managing complex attachments and boundaries

As discussed in the previous subtheme, close relationships were something for homecare workers to strive towards, yet they were also required to maintain professional emotional distance. In this subtheme, I highlight some of the challenges associated with developing close homecare relationships, such as where complex mutual attachments formed, or tolerating sexualised behaviours became a normalised part of the job.

Homecare workers described finding it difficult to manage the emotions associated with forming these relationships, within the professional boundaries of the role:

'I think we get quite attached to her as much as she's got attached to us really... it's like being with your gran. We're not supposed to get emotionally involved, but I think we're all human beings.' (Homecare Worker 18)

Both clients and homecare workers reported having 'favourites'. As such, homecare workers described finding it hard to leave certain clients, often staying on in their own unpaid time. This could be due to enjoying spending time in the company of their clients and family carers, as exhibited by some homecare workers who spent their lunch breaks with their clients, or because of a heightened sense of responsibility for clients, particularly for those who lived alone. There was a sense in many narratives that work and contact with clients outside of contracted hours were virtuous and a sign of doing the job well:

'Sometimes, I can be there for the next half an hour, but I don't care, just knowing that I'm doing something good. So I try to make her as comfortable as possible because she's on her own.' (Homecare Worker 10)

We observed situations where homecare workers brought flowers, food and home-baked goods for clients. I sketched a scene showing the flowers that a

homecare worker (Audrey) had bought for her client (Beatrice) to 'brighten her day' (Figure 5.4). Some homecare workers reported maintaining contact with people living with dementia and their family carers, long after they stopped providing their homecare support (i.e. due to reallocation of homecare workers or homecare provider when the client moved home). In one such situation, a homecare worker reported visiting a past client in her own time as a personal favour to the family, even taking the family carer out for lunch in her break, between her scheduled clients' visits:

'In the car, Alison talked about a previous client whose homecare was reassigned to a different agency when the family moved home a number of months prior. Alison tells me the family carer is unhappy with the new agency, so she sometimes still visits them in her evenings and helps the person with dementia with tasks such as shaving, as a favour to him and his family carer.'

(Agency 4)

Figure 5.4: Observational sketch - Audrey bought flowers for Beatrice

Forming emotional attachments to clients and their family members, could become particularly difficult when the homecare worker's contact with them ended. This occurred for several reasons, including when the client's homecare schedule was reorganised and different homecare workers were assigned, when the client went into hospital, ending their homecare contract, or when clients died:

'April spoke about a previous client with whom she had developed a close relationship, who went into hospital several months ago. April talks about missing her, and is struggling with not knowing the outcome of what has happened to her. All she knows is the client is not on the agency's books right now.' (Agency 4)

Homecare workers reported finding it particularly difficult when their clients living with dementia died. In one case, a homecare worker reported 'dreading' the loss of her favourite client but did not know of any support to help her deal with this. A homecare manager from one of the smaller agencies reflected on the emotional impact felt by homecare staff, including herself as a manager, when clients died; suggesting that grief was felt across the entire agency as the client's care provider:

'I have to deal with then, the deaths of clients and it hits my staff really, really hard… I go to funerals of clients and people say sometimes you get hardened to things, but you don't.' (Homecare Manager 7)

Where female homecare workers supported male clients living with dementia, there was a sense that the homecare workers accepted romanticised or sexualised language or behaviours as a sign of positive relationships. With two male clients, the homecare workers frequently used terms of endearment such as 'handsome' and 'trouble', while one client referred to his homecare worker as 'baby'. This client also often inappropriately touched his homecare worker while she changed his clothes; the homecare worker responded with humour in return and would also retaliate with similar romanticised behaviour, offering the client a kiss on the cheek as a reward for taking his medication:

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'Alison places a jumper over Benji's head and he puts his arms through and then rolls the sleeves up. As Alison neatens him up, Benji maintains physical contact with her throughout. He holds onto her arm and strokes her, then puts his arm around her waist… Alison helps Benji to stand up. Benji puts his arms around Alison and cuddles into her. Alison hugs him back and says aloud that now it's the part where they have a cuddle.' (Agency 4)

The homecare worker perceived the relationship she had with this client favourably and felt these strategies enabled her to complete tasks with him.

5.2.3   Theme three: Managing risk, resistance and behaviours that challenge

In this theme, I consider the skills and support homecare workers need when managing difficult situations, including when clients refused or resisted care. In the first subtheme, I explore situations where clients living with dementia presented with behaviours that challenged, such as during personal care tasks. In the second subtheme, I consider issues around providing care when clients who lacked capacity refused or resisted care. Across both subthemes, I explore the strategies used by homecare workers to manage in these situations and the skills required to enable safe and effective care.

5.2.3.1   Subtheme A: Managing behaviours that challenge

In this subtheme, I explore the skills required by homecare workers to understand how to manage risk and to provide safe and effective care to clients living with dementia in difficult situations, such as when clients presented with behaviours that challenged. I observed a situation where a client was frustrated at being told she must stay in bed (a decision made by social workers and family carers due to deteriorated mobility); the homecare worker appeared unsure how to respond, beyond attempting to distract the client with an offer of something to drink:

'Beatrice remains very distressed and shouts to be left alone. Audrey appears deflated but offers Beatrice a drink again; she pushes the cup away. Audrey comes over to me to apologise, saying "it isn't very nice when Beatrice is like this".

Beatrice's distress has been ongoing for 25-minutes and she remains asking to go to the toilet. Audrey has stopped responding.' (Agency 4)

Beatrice would often try to get herself out of bed, asserting her independence and desire to be mobile, yet this posed significant risks for both the client and homecare worker. During one visit, Audrey was observed to be 'physically keeping Beatrice on the bed with her own body', to prevent Beatrice from falling out of the bed as her frustration increased.

Homecare workers reported that clients often displayed behaviours that challenge during personal care provision. In the example below, the researcher-observer's narrative describes the client's behaviour as 'putting up a fight', in congruence with observing the homecare workers struggling to provide personal care while the client presented as agitated and distressed throughout the visit:

'Beverly is very agitated this evening and constantly rubs her legs and body up and down the whole time we are there. There is no teeth brushing and there is limited offering of juice. Ashley does a very quick wash of Beverly's face and bottom. They do not change her top. Beverly puts up a fight when Ashley tries to wash her face or wash her/change her pad… Beverly shouts and swears more. She asks the home carers multiple times to go, or asks when they are leaving/how long are they staying. Things feel more rushed although fewer tasks are delivered than normal.' (Agency 3)

In this situation, the homecare workers responded by attempting to work faster and attending to as much of the client's personal care as was manageable; even though this was less than normal.

Across interviews and observations, managing risk and behaviours that challenge was a prevalent theme in the narratives of family carers, homecare staff and health and social care professionals. Homecare workers and managers described how training and support were important to equip homecare workers with the skills to manage such challenges, including where clients were verbally or physically aggressive. In the example below, a homecare worker uses combative language when referring to such

support as 'armour' and metaphorically likening clients living with dementia as 'wolves':

'… [for someone] to be at the end of the phone, to say "look, I need somebody else here, this is getting a bit out of hand". Then the support would have to be there, wouldn't it? You can't just put somebody in a situation with no armour, as such… You've been thrown to the wolves, haven't you? You've got no training, how are you supposed to deal with somebody, with an illness that you know nothing about?' (Homecare Worker 19)

Understanding behaviours that challenge as a form of communication was described as important by all participant groups; facilitated by homecare workers being familiar with the client, in order to understand the meaning behind the behaviours, as well as skills of empathy. One family carer considered the experience of pain as a reason why a person living with dementia might present as challenging, particularly if they are unable to verbally communicate this:

'They might have toothache… When they start lashing out and becoming… Oh people say "well they're a difficult person". No, it's probably because they've been in pain for a long time and besides, they're also out of their mind from the pain and they're tired from it, and they get angry.' (Family Carer 22)

Yet in observations, behaviours that appeared to challenge homecare workers, particularly non-verbal behaviours, did not appear to be interpreted as a form of communication and were dealt with by rushing through care or working faster to get through the moment.

Experiential learning could enable homecare workers to develop these valuable skills, including empathy. One homecare worker discussed encouraging others to try being moved in a hoist during training, to experience what it felt like:

'And I made her [another homecare worker] sit in the hoist… made her lie on the bed, rolled her, used the slip and slide sheets. Because my point of view is, if I haven't done it, or I haven't sat in that, how do I know how comfortable it is for my

5.2.3.2 Subtheme B: Considering capacity

It could be difficult for homecare workers to navigate between providing care that was in the clients' best interest, such as keeping them clean, and preventing infections or bed sores, and respecting the client's wishes when they resisted or actively refused care. When clients living with dementia did not have capacity to make decisions around their care, one homecare manager discussed how homecare workers can 'guide' clients to accept care if they do not have capacity to understand what is happening and why:

'We don't want to force anyone. If they haven't got capacity to make that decision, we've got to guide them, and try our best. But we can't pin them down and strip wash them, or force their medication down their throat.' (Homecare Manager 6)

We observed examples of homecare workers trying to guide their clients to accept care, or in other words to provided necessary care with assent, where clients lacked capacity to consent. In the example below, the client living with dementia verbally protested against the homecare workers changing her pad. In this situation, the homecare workers spoke calmly, explaining to the client what they were doing and why, and gave her some time to calm down before trying again:

'Alison and April told Beth they were going to give her a pad change and began to pull away her bed covers. Beth held on tightly to the covers, saying "no please don't, I don't want you to", saying that she was "frightened". Both April and Alison tried to reassure Beth and repeatedly explained what they were doing and that is was to make Beth more comfortable. Beth protested and said she already had her pad changed. Alison explained calmly that was this morning and it had to be done again at lunch… April and Alison both stopped touching the covers and tried to tell Beth that she was okay. Alison stepped back and said to Beth that she would raise her bed and lower her head to make it better.' (Agency 4)

At the end of the visit 'Beth thanked both carers for helping her and said that she recognised both of them', suggesting that familiarity with the homecare workers may have also helped in this situation. Moreover, the person living with dementia was able to vocalise feeling 'frightened', which the homecare workers responded to calmly, slowly and with reassurance. This contrasts with the examples of Beatrice and Beverly presented previously, where these clients were less able to vocalise their discomfort; perhaps because the homecare workers did not understand the source of agitation or know how to address it; they saw using distraction or working faster to reduce the duration of distress as the only available options.

When clients refused care but did not have capacity to manage risk or make good decisions around their care, this was sometimes perceived to pre-empt a move to a care home:

'Although he didn't have full capacity to say I need people around me all the time, he needed more people around, more of the time, and the family weren't receptive to that, unfortunately. I mean, he's probably getting the care he needs in the care home now.' (Homecare Worker 14)

5.2.4   Theme four: Agency and team support

In this final theme, I consider the role of homecare agencies/managers in supporting homecare workers who provide care to people living with dementia. In the first subtheme, I explore the emotional support needs of homecare workers, such as grief support for when a client dies, and in the second subtheme, I discuss the practical support needs of homecare workers, such as scheduling that allows time for breaks.

5.2.4.1   Subtheme A: Emotional needs

In this subtheme, I draw upon emotionally difficult situations that homecare workers faced and discuss managerial and peer support strategies. Homecare workers often worked in isolation, with limited regular contact with other homecare workers or the homecare agency. They described feeling a lack of emotional support when challenges with clients arose. In the example below, one homecare worker described having no opportunity to debrief with colleagues after a difficult visit with a client:

'I think it would be nice to have somebody… that if it got too much like it was with [Client], that they could understand how I felt that day… And afterwards, I cried all the way home…' (Homecare Worker 19)

Not all homecare workers worked in isolation. In some cases, they worked together with the same client(s). One homecare worker who was part of a team providing a 24-hour care package, reported feeling 'lucky to have a good team around' her, describing her relationship with the other care workers as 'a close unit' and 'supportive' (Homecare Worker 18). This was further evidenced in this particular homecare worker's narratives in both her interview and during observations, where she referred to 'we', regarding any decisions made around the client's care.

Some homecare workers sought informal peer support during joint shifts. This may have been their only opportunity for this, but could lead to homecare workers chatting or venting their frustrations in front of clients and their family carers:

'Alina and Ashley talk to each other while they work and laugh together. Belinda gets distressed again by this and shouts. Alina says again that they are not laughing at her and says sorry.' (Agency 3)

'They shouldn't be talking [about] their personal issues. Yes, because I don't want to know, and obviously they discuss things what happened last week or yesterday, I'm not interested.' (Family Carer 19)

In some observation visits, homecare workers would vent to the researcher-observers, highlighting limited opportunities for peer support:

'Angela continues to express her frustrations and tells me that Betty's cleaner has been off work so she has had to also take on the responsibility of cleaning Betty's home more than she usually would. I sense that Angela sees me as someone to vent her frustrations to - I wonder if she has other support to turn to when she has complaints about her work.' (Agency 1)

At a later visit, Angela expressed wanting to discuss her problems with someone but 'realises there isn't that someone to talk to'.

Homecare staff and health and social care professional participants discussed the often-challenging nature of the homecare role and the importance of supportive managers. Supportive approaches included managers adopting an 'open-door' approach and office staff being contactable to provide support at all times:

'Most of them [the homecare workers] will tell you that I'm a really caring manager. I look after them. I've always got an open-door policy.' (Homecare Manager 7)

'I was able to go to my employer and say, "I don't really know how to approach this. How can I do this?". They called me back and it was just helpful to just be talked through some techniques. It was just over the phone, but it was perfect for the situation.' (Homecare Worker 14)

Such strategies helped some homecare workers to feel less isolated in their role when supporting clients living with dementia. We observed shared communal spaces in some agency offices where homecare workers visited for both formal supervision and peer or managerial support. Figure 5.5 shows a table and chairs in one agency's outdoor communal space. Homecare workers were frequently observed sitting around the table during their breaks (the agency was located in close proximity to many clients' homes), catching up with office staff and other colleagues, and interacting with the two office dogs. In this particular agency, it seemed that homecare staff knew each other well and many socialised together outside of work. Figure 5.6 captured another agency's basement area, where the communal space was used for team meetings and staff training, as well as staff birthday celebrations, as evidenced by the balloons on the wall:

Figure 5.5: Agency's outdoor communal space

Figure 5.6: Agency's basement communal space

5.2.4.2 Subtheme B: Practical support

In this subtheme, I consider some of the practical support needs of homecare workers, and the strategies that agencies could adopt to facilitate homecare that responded to clients' needs, while protecting the wellbeing of homecare workers. Poorly organised visit scheduling caused frustration for all participant groups. For homecare workers, short-staffing and visit-cramming led to little time for breaks, self-care, or even time to attend training:

'We did a Care Certificate and I'm pretty sure we did some dementia training... Sorry, I'm yet to do it.... I was working when it was on.' (Homecare Worker 26)

'Before falling ill, April told me she never ate, drank or went to the toilet while she worked because she didn't have time to.' (Agency 4)

Some homecare workers felt unsupported when managers did not take their personal lives into account when scheduling visits, such as childcare responsibilities. In one example, we observed confrontation between a homecare worker and her manager, when she had been scheduled to work on Christmas Day:

'Amy explained again that she cannot leave her younger child who is autistic at home alone without care. The manager told Amy that he wasn't happy about it but the other [female] manager had said to give Amy those days off for her children, but she had to work for 4-hours on New Year's Day from 7-11am.' (Agency 4)

Homecare workers faced challenges when they were scheduled to visit a new client at short notice, as well as when clients living with dementia were only allocated short visits (i.e. less than 30-minutes); this happened more with clients whose care was funded by the Local Authority. All participant groups acknowledged that people living with dementia needed more time than clients without dementia, and homecare workers required longer visits to support and get to know them. As reported in the example below, some agencies had a policy of one-hour minimum visits in which to see clients; albeit in this particular agency, the majority of clients privately funded their care:

'…this is why at [Homecare agency], when we go to visit clients, we have a minimum of an hour because we know, coupled with their ageing process and with dementia, processing information is very difficult… they take a long time to do that. It's just allowing them that time, you see, to do as much for themselves as possible.' (Homecare Office Support Staff 1)

Homecare workers cancelling their visits or calling in sick at short notice occurred frequently, and agency staff were observed spending much of their time trying to

ensure that clients were cared for, by finding another care worker to 'cover' the visit. We observed office staff continuously calling or sending texts to homecare workers during visits, while trying to find cover for other clients. As in the example below, this could be disruptive and distressing for both the homecare workers and their clients during visits:

'While Amy is washing Beth, the phone in her back-pocket rings and she answers the call. It is the agency asking her to cover a shift. Amy continues to wash Beth's private areas as she speaks on the phone. Amy moves towels over Beth's body to keep her warm. Beth is silent. …Amy's phone rings once again (it is the third time in 20-minutes). She looks at it, announces it is the agency and rejects the call.' (Agency 4)

Homecare workers often felt pressured to take on extra work, sometimes working long days without breaks. Some reported doing so out of loyalty to the homecare manager or office support staff, a responsibility to make sure clients were cared for, and/or because they needed the money that would come from working extra shifts. Taking on additional work covering for other care workers became a normal routine for many homecare workers:

'I ask Aida about her routines and visits and Aida explained that she does up to 7 shifts per week with Bara at different times and different days of the week, including weekends. At the moment they are not set days/times due to covering for other carers.' (Agency 5)

Providing cover for a homecare worker who had called in sick could be difficult for homecare workers, as it required them to provide support to a person living with dementia that they knew little about. Likewise, it could be unsettling for clients living with dementia and family carers when unexpected homecare workers arrived who were unfamiliar with the client or their routine:

'Before they used to give her a carer, a different carer everyday sort of thing and that was just doing our head in because we have to explain to them every day like

what she needs to be done and stuff like that they don't read the file or whatever.'

(Family Carer 18)

For clients living with dementia and their family carers, this lack of consistency and regularly seeing unfamiliar homecare workers was one of the main sources of frustration that was both discussed and observed. In addition, disruption to their routine was also caused by homecare workers having busy schedules which could affect their reliability and punctuality:

'I know how difficult it is for [homecare workers] to stick to a sensible timetable. But, I don't want to be greeting visitors unless I'm half dead at 11 at night when they should have been there at 10 in the morning.' (Person Living with Dementia 16)

'When Cameron answered the door, Alyssa told him Amy was on her way. Cameron commented that they [the homecare workers] "keep getting later and later".' (Agency 4)

Relating to the example above, we observed the negative impact such delays had on the family carer who was scheduled to receive two respite visits per week. On a number of occasions, Cameron missed his social events with his sports club because the homecare worker arrived late to the visit.

Homecare workers were sometimes visibly tired during visits. We observed a homecare worker fall asleep during a 'sitting service' (a longer duration respite visit) and another who cut herself badly while washing-up a client's dishes. Some homecare workers became ill during the study and needed time off to recover, while others continued working and visiting clients whilst unwell, as in the example below:

'Alina chats to me quietly about how she has been. She is ill with a chesty cold and is seven days in to a 10-day shift. She says she didn't sleep well last night and slept through her alarm this morning which meant she was late for her first client and this appointment. She informed the office and they arranged for a different home carer to go to the shift after Beverly so that Alina can catch up'. (Agency 3)

The possibility of passing on illness to clients who were vulnerable was perhaps overshadowed by staff-shortages and a responsibility to make sure that all clients received their homecare.

5.3   Summary

In this chapter I have presented my findings in response to the skills, training and support needs of homecare workers for people living with dementia. I have outlined the different identities and roles that homecare workers adopted in supporting clients living with dementia, and the associated tensions and expectations that arose without role clarity, or where role expectations differed between stakeholders. I explored the relational and emotional skills that homecare workers needed to develop important relationships with clients and family carers and to manage complex attachments and boundaries. Homecare workers faced difficulties in providing safe and effective care to clients who displayed behaviours that challenge, particularly during personal care. We observed examples where verbal expressions of distress elicited more positive responses from homecare workers than non-verbal distress, suggesting that understanding or interpreting non-verbal communication in caring for clients with dementia may be a training need.

Facilitating opportunities for peer support and managers adopting an open-door approach were seen as ways to support homecare workers' emotional needs, while incorporating breaks and avoiding visit-cramming could support their practical needs. An overarching strand running through these findings was the relationship-focused aspects of homecare, and thus of the training and support needs of homecare workers. The themes I identified described the importance of homecare workers' relationships with their clients living with dementia, family carers, homecare staff and other professionals, and how the different roles homecare workers take can influence these relationships. Within the homecare worker-client relationship, the need to manage behaviours that challenge was identified as a key training need, and it also engendered homecare workers' own support needs, which could be met through peer and managerial supportive relationships.

Chapter 6   Supporting independence in people living with dementia

In the previous chapter, I responded to the broader aim of exploring the training and support needs of homecare workers who care for people living with dementia. In this chapter, I will narrow my focus to a topic pertinent to the NIDUS programme: how homecare workers support or inhibit independence in their clients living with dementia. This question is distinct from that discussed in the last chapter, though unsurprisingly the findings are inter-related. Homecare worker training and support needs will include the need to deliver care that enables independence, but are wider than this, for example encompassing how to preserve client dignity, compassion, and safety.

Homecare workers supporting independence in clients living with dementia will draw on the relationship-focused aspects of care described in the previous chapter. In this chapter, I also discuss themes that extend to the homecare environment, managing inherent risk, and power dynamics within the care team, as well as drawing out the central importance of knowing the client when enabling independence. Where the themes I outline below in response to my second research question relate to those in the previous chapter, I will comment on these links in my discussion chapter (see section 9.1.2) where I present an integrated summary of the findings described in this and the previous chapter.

A version of this analysis has been published in *Social Psychiatry and Psychiatric Epidemiology* (Leverton et al., 2021a) [see Appendix 19].

6.1   Qualitative analysis

Across the interview and observation data, I identified three themes. These were: 1) 'Independence and the home environment', 2) 'Independence and identity', 3) 'Independence and empowerment'. As in the previous chapter, I have presented example quotes from interviews in 'blue' and observations in 'green' to aid comparison across both methods of data collection. The identity of participants has been anonymised using ID numbers to represent interview participants, and observation participants have been anonymised using pseudonyms: 'A' names for

homecare workers, 'B' names for people living with dementia, and 'C' names for family carers.

6.1.1 Theme one - Independence and the home environment

In this theme, I explore the home environment as a site of care that enabled independence through familiarity, yet at times also presented barriers to it. This was a recurring theme that was most prevalent from the observation data. Clients' care needs and the needs of homecare workers providing care often necessitated some degree of negotiation with the space available. I identified three subthemes, exploring the home environment and its: a) transition into a hybrid environment between the client's private, domestic space and the homecare worker's workplace, b) suitability in which to provide and receive care, and c) how decisions about environmental adaptations need to balance risk and independence.

6.1.1.1 Subtheme A: The home as a hybrid space

In this subtheme, I present some of the changes made to clients' homes, when their ability to remain independent became more limited. The environment often shifted from a wholly personal, private space to something resembling a workplace for homecare workers. This blending of functional spaces meant that the home contained visible signs of disability and care, with bags of disposable gloves and continence pads, adaptations to bathrooms, and living rooms converted into bedrooms. In the example below, one client's dining table had been repurposed as a space for communication between homecare workers and family carers about the client:

'Annie says that the dining table is used to leave messages to those involved in Benita's care – e.g. a folder that bills are put into for the family to pay, notes for other homecare workers, cards to be posted etc. Annie apologises to me that it looks messy.' (Agency 5)

Some care professionals and homecare staff viewed adaptations made to clients' homes as a positive change, with one health professional perceiving such changes

would be willingly accepted by people living with dementia, where this enabled continued living at home:

'They're quite willing to actually then introduce bits and pieces into their current living situation to enable them to remain independent... Like, one floor living for example or adapting the bathroom or introducing aids in the kitchen or something along those lines.' (Health & Social Care Professional 15)

While acknowledging that trade-offs that enabled continued living at home could be accepted in preference to a move to a care home, even where this involved limiting one's existence to one floor of the house, such adaptations could overshadow the familiarity and personalisation of the home for people living with dementia. Whilst adaptations intended to promote functioning, they could also be depersonalising and perhaps even institutionalising. One homecare worker vocalised the need to find a balance between making necessary changes in the home to support independence, without causing upset to the person living with dementia:

'I've got to understand that [the home], that's theirs and I can't change it. But if there's a way that it can be changed but it's not going to be too upsetting for the client, then we'll work together.' (Homecare Worker 21)

As well as the presence of care equipment, we also observed homecare workers leaving their personal possessions such as slippers and other belongings in clients' homes. In the example below, a homecare worker stored her bike in her client's home, against the wishes of the person living with dementia:

'There is a bike obstructing the hallway – Audrey tells me that one of the other homecare workers had left her bike in the house while she was on holiday. Beatrice had noticed a few times and asked for it to be taken out of her home.' (Agency 4)

In this example, the homecare worker leaving her bike in the client's hallway suggests that the client's home was not always understood as a private space. Beatrice's reported requests for the bike to be removed were unheeded, which may signify a loss of control over her home. While some agency offices had communal spaces as

described in the previous chapter, homecare workers did not have a space of their own to store their work files, care equipment, nor their personal belongings. They spent most of their working day in clients' homes, so perhaps understandably perceived their clients' homes as their workplace.

There were numerous examples of homecare workers taking pride in their clients' homes, as in the example below where the homecare worker tended to the aesthetics of the person living with dementia's home:

'Angela tells me to follow her into the back bedroom to look at the view of the garden from upstairs. She has much pride in Betty's garden… Angela also shows me that she brought out some of Betty's crystal jars, cleaned them and has now started saving flower petals and putting them in these jars to dry them out to keep the house smelling nice.' (Agency 1)

Caring for the home can perhaps be considered an extension of caring for the client, but this may also suggest a blurring of boundaries around ownership of space; the home risks being perceived, erroneously, as a hybrid space in terms of ownership as well as function. One homecare manager reported reminding her care staff of their position as a guest when in the homes of clients living with dementia:

'I say, at the end of the day, we are walking in their shoes and that's a really important thing to remember… I always say that to staff, I say, "please remember that you're in their homes, you're a guest in their home. You must treat them with the respect and the dignity they deserve".' (Homecare Manager 7)

Perhaps this description of being a guest in their clients' homes, and a visitor in agency offices, speaks to the isolated and transitory nature of the homecare role and the need for some homecare workers to feel a sense of personal belonging in their work, and in clients' homes.

6.1.1.2   Subtheme B: A familiar but unsuited environment

In this subtheme, I consider how independence for people living with dementia is supported by familiarity, but this could also be challenged when clients' homes were

not well suited for care provision. In interviews, all participant groups described simply 'being in their own home in their own surroundings' (Homecare Worker 19) and the ability to 'move freely around their home, to do whatever it is they want to do' (Homecare Worker 17) as important for people living with dementia to maintain independence. Yet on numerous occasions, we observed frustrations that the home environment was not better adapted to enable care, and how independence could be curtailed, for example, by the necessity for 'single-floor living'. A negotiation of space required homecare workers to make the available space work for the care that the client needed, although this could be to the detriment of the clients' dignity, where there was limited space for personal care, or autonomy in accessing parts of their home. In the example below, we observed how a client living with dementia was restricted to moving between only two rooms in her room due to the size of her wheelchair that was needed to aid her mobility:

'Audrey tells me that they [the homecare workers] are unable to fit the wheelchair through the door frames so Beatrice mainly spends her time between the TV room and her bedroom next door.' (Agency 4)

The layout of the home and availability of space in which to perform certain care tasks could also be at detriment to the homecare workers' time, efficiency or own safety and wellbeing. In the above example, a decision was later made to keep Beatrice in bed as a result of her deteriorated mobility. This created further challenges for the homecare workers:

'Audrey and Anna update each other on how Beatrice has been for ten minutes while in the room with Beatrice. They both discuss finding it difficult to change Beatrice alone while she is in the bed. Anna reports that Beatrice let her roll her over yesterday so she could check the pressure of the bed'. (Agency 4)

Both Audrey and Anna were observed sitting or standing in uncomfortable positions at times, manoeuvring around a large fall mat beside Beatrice's bed as well as other bedroom furniture, in order to wash and change Beatrice, and support mealtimes. I sketched the setup of Beatrice's bedroom (Figure 6.1):
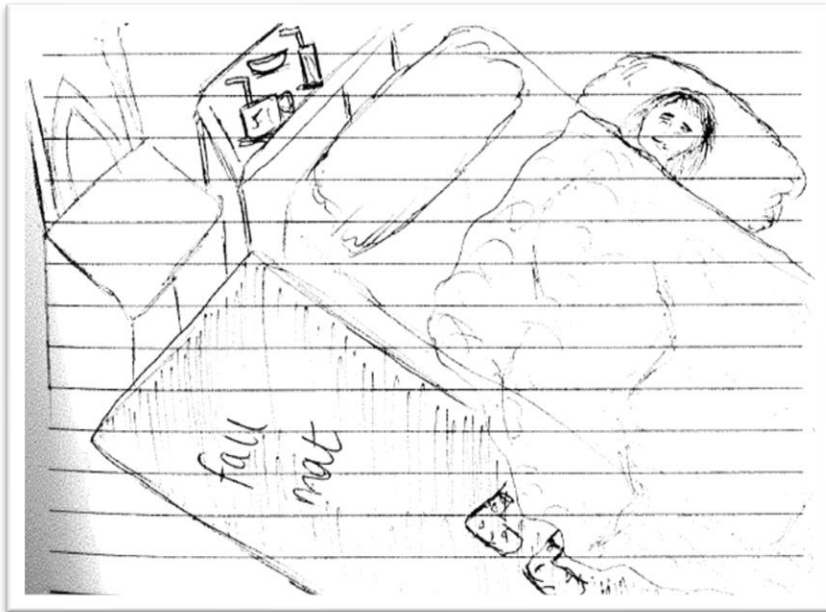
Figure 6.1: Observation sketch - Beatrice's bedroom set-up

In another example with a different client, the carpeted floor of the client's home, which in other circumstances may have been preferable and contributing to a homely environment, caused difficulty when manoeuvring the hoist. On one occasion, this resulted in the homecare worker bumping into a table whilst supporting the client:

'Amy manoeuvres the hoist as Ava holds Beth's legs still. Amy struggles to swiftly manoeuvre the hoist on the carpeted floor having to put physical effort into pushing it. Amy bumps into a table as she does this which jolts Beth.' (Agency 4)

In contrast, we observed homecare provided to a person living with dementia and family carer dyad who had recently moved to a new house, due to a decline in the client's ability to independently manage daily life. The new home was more accessible with a wet-room equipped with rails and storage space for personal care supplies. However, despite the accessible space and equipment, the unfamiliarity of the new bathroom was experienced as distressing for the person living with dementia, who often resisted entering the bathroom:

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'I stood outside the door as the bathroom has limited space. Caroline informed me earlier that Brian finds the bathroom claustrophobic and they [the family carer and homecare worker] often have trouble getting him in there.' (Agency 4)

In the above example, the homecare worker managed by providing Brian's personal care in the living room where he was more comfortable. Although the living room is not the ideal place to provide personal care, by being flexible and person-centred, the homecare worker was able to support Brian to remain clean; yet the potential costs of this were risk of falls or injury to either the client or the homecare worker.

6.1.1.3 Subtheme C: Safety and risk

In this subtheme, I consider risks relating to the home environment, and the strategies used by homecare workers to balance independence and safety for people living with dementia. In particular, for clients who were more mobile around the home, there were often associated risks such as falling. We observed one client who lived alone, in a house with a steep staircase; the homecare worker had reported feeling 'unsteady' on it herself. This exacerbated the homecare worker's concerns on visits where the client was slow to open the door or failed to answer when she arrived:

'The atmosphere felt tense while standing outside Bernice's door as Alison attempted to gain entry. After several times ringing the front door, Alison asked the agency to call Bernice's house phone which she did not answer. Alison sighed and said she didn't think it was fair that Bernice lived on her own.' (Agency 4)

As considered in the previous subtheme, concern around the suitability of the home environment was often accompanied by an uncertainty of whether the risks of living alone were justified. Homecare workers are employed to enable people to live at home, but they may not necessarily consider this to be in the clients' best interests. Alison felt that it was 'unfair' that Bernice lived alone, whilst Bernice used a chair to barricade her front door overnight. Another client expressed feeling 'vulnerable' (Agency 5) while waiting for his wife to return home after the homecare worker had left.

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Risks associated with the home environment were also a concern for family carers, on whom proxy-decisions about how much risk to accept to enable continued home living sometimes weighed heavily. Whilst living at home and maintaining independence was reported as a priority for people living with dementia, family carers were more concerned with strategies to prevent risk in the home:

'I think she is entirely fed up with me, I think she sees me as like a jailer really. Which I'm not, I'm only trying to prevent her falling or helping her... It's difficult to judge the line.' (Family Carer 32)

Professionals also spoke of the need to find a 'balance', where people living with dementia can maintain 'their right to independence', with the associated need to 'manage risk' (Health and Social Care Professional 13). A trade-off was described in which a certain level of risk had to be accepted to support independence:

'...you can only keep them as safe as you can. There will always be falls. I was always taught that if they're not falling then they're not living. Because they're not moving around, you see?' (Homecare Worker 28)

One response to managing risks was to close-off and restrict access to parts of the home to the person living with dementia. This was observed in varying degrees, from a locked medicine cabinet, to a locked bathroom, to a locked stairgate restricting the client from accessing the first floor of her home without support:

'Angela described how after some prior risk incidents with Betty they had to lock away much of her house and move her bedroom downstairs. Betty can now only go upstairs with assistance from the homecare workers. Angela said she doesn't like doing this but it keeps Betty safe when she is on her own.' (Agency 1)

During another visit with Angela, Betty acknowledged her shrinking environment:

'...Angela reminds Betty that her bedroom is now downstairs. Although jovial, Betty compares this to a dog being locked out of its room. Angela reminds Betty that her cousin Cliff had asked for this in order to keep her safe. Betty says that she knows this and isn't complaining really.' (Agency 1)

6.1.2 Theme two: Independence and identity

In this theme, I consider how understanding the identity and personhood of people living with dementia was central to supporting their independence, for example through greater understanding of the choices and decisions people valued. Homecare workers offered choices, however doing so with clients with more advanced dementia was less successful in terms of appearing to elicit a meaningful choice. In the previous chapter, I considered the importance of establishing a clear role identity for homecare workers, with a key part of that identity being the formation of good relationships with clients living with dementia. In this theme, I consider in turn how understanding and valuing the identity of a person living with dementia as an individual could be considered a prerequisite to supporting independence in people living with dementia; facilitated by homecare workers getting to know the client and building close relationships.

I present this finding across two subthemes. In the first subtheme, I explore identity as a stable concept, before and after a person develops dementia. In the second subtheme, I consider how homecare workers can support their clients to stay involved in their daily tasks and in making informed choices, as individuals with functional abilities.

6.1.2.1 Subtheme A: The past versus the present self

In this subtheme, I present a disparity between participants' narratives in interviews and the pragmatism observed during homecare for people living with dementia. Whilst there were differences in the data collected by these two methods, there were also tensions between discourses of participants in interviews when considering personhood and identity of people living with dementia. This concerned a perception of who they *used to* be before developing dementia (as in the former quote below) and the person they are now (the latter quote below):

> 'This is a person who may have had a fabulous career… they've had a life. And recognise and appreciate that they've had a life.' (Health and Social Care Professional 21)

'I don't think that the dementia is overruling her because there's still a whole lot of her there… Her fun-loving personality, her wit, her intelligence, her care, her happiness is still there. But she just doesn't know where she lives.' (Homecare Worker 21)

All participant groups described that acknowledging and valuing the personhood of people living with dementia was a prerequisite to enabling independence. In the example below, a person living with dementia commented that being diagnosed with dementia does not change or replace the individual's identity and homecare workers need to respect their clients for the person they still are and what they remain able to do:

'We all had talents before dementia; we don't suddenly lose those talents overnight when we've got a diagnosis. And to remember that we were once a working person and a totally capable person. So to remember that there's been a person there that still can do things.' (Person Living with Dementia 17)

Being able to connect the past with clients' present lives was considered an important skill for homecare workers; to be able 'to see their clients… to have some understanding of where they have come from' (Family Carer 11). As explored in the previous chapter, getting to know their clients and developing close relationships facilitated this, and could enable homecare workers to understand and value their clients as individuals beyond their dementia diagnosis. Care provided in clients' homes also facilitated this, being surrounded by their life memories and possessions that homecare workers could utilise to 'understand' them, and to connect their life history with their present self:

'We have a chap who… he was one of the first British soldiers to get captured and he spent the whole of the war in a prisoner of war camp. And he got out the photographs and he showed me, and he was the comic variety… could sit and talk for hours and hours and it obviously made him very happy… so it was always a good starting point for the homecare workers.' (Homecare Manager 1)

While participants in interviews described the importance of valuing personhood and providing person-centred care to people living with dementia, our observations suggested that in reality, doing so was less straightforward. In some observations, particularly with people living with more advanced dementia, there was a sense that their identity and personhood were becoming challenged or lost. Sometimes homecare workers tried to maintain who or how they perceived the client to have been in the past, even if this was no longer what the client wanted, as in the example below:

'Ashley wonders if there is any make up in the house and goes to the bathroom to look. Alina asks Belinda if she wears make up. Belinda replies "no"… Ashley looks through Belinda's dresser drawers to see if she can find make up.' (Agency 2)

In other situations, we observed homecare workers using infantilising language or behaviour with their clients living with dementia. In the example below, the client was able to challenge this:

'Amy tells Beth that she's going to "give her little feety a wash now", to which Beth exclaims "I don't have a little feety, I have a foot!".' (Agency 4)

6.1.2.2   Subtheme B: Staying involved and making choices

In this subtheme, I explore how involving clients in their daily tasks and decision-making supported people living with dementia to maintain independence. Some homecare workers were observed encouraging their clients to try smaller or simplified parts of tasks, keeping them included as an active participant in their care. We observed the effect of different approaches taken by two different homecare workers with the same client. In the first example below, the homecare worker explained to the client what she was going to do, but did not involve the client in the task, unlike the second example where the homecare worker invited the client to try doing parts of the task for herself, resulting in a more positive outcome:

'Amy told Beth they were going to wash her face. As she begins, Beth asks what she's doing with her face and Amy explains again. Beth says that she's not used to

being washed and dressed by other people, she's used to doing it herself and begins to cry.' (Agency 4)

'Alice told Beth they were going to wash her hands and then asked Beth if she would like to try washing herself as it "might be good for her" to do this… Beth was able to use the flannel to wash most of her upper body, while Alice provided step-by-step instruction to Beth which she was able to follow well – e.g. "now use this hand and wash under this arm", while touching each to guide Beth.' (Agency 4)

In interviews, all participant groups highlighted what good practice in supporting independence may look like, including the importance of involving people with dementia in their everyday tasks, even 'if they can't do it in a way that we expect it' (Homecare Office Support Staff 02). Enabling clients to remain as active participants in their care often involved encouragement and making small adaptations to facilitate the client's existing abilities, as described in the examples below:

'I think the majority of people would still want to do things for themselves. So it's getting over what you can advise the person, like if the person can't tie their shoelaces anymore, then advise them and the family to get slip-on shoes.' (Person Living with Dementia 17)

'Actually, when you're lonely and isolated and you've got dementia and things like that, having someone that encourages and sees the positive and builds you up is really important.' (Family carer 19)

However, as we observed, achieving this in practice was more challenging. Homecare workers often made attempts to offer choice and support autonomy with clients living with dementia, yet as in the example below, this sometimes seemed less meaningful with clients who were less able or unable to make choices where they were offered:

'Anya asked Belinda if she would like a coffee. Belinda says "yes". Anya says "you did not drink your coffee shall I make you a tea?" Belinda says "yes tea".' (Agency 2)

Time constraints were also observed and identified by participants as inhibiting homecare workers from involving people living with dementia in everyday tasks. As presented in the findings of the previous chapter, short visit times could be stressful for homecare workers, sometimes leading to rushed visits for clients, without opportunities to participate in care tasks. I observed a 15-minute homecare visit where the homecare worker arrived to find the client's home in a messy state, with furniture moved around in the living room and the kitchen surfaces littered with used matches, cigarette butts and half opened wine bottles. Deeming this a potential hazard for the client, the homecare worker prioritised cleaning up the kitchen whilst the client sat alone in the living room. I decided to sketch the kitchen sink area in Figure 6.2, as I was struck by the scene and wanted to highlight why the homecare worker might have felt the area was unsafe to leave for the client. In doing so, this left only five minutes to tend to the tasks in the care plan: supporting the client to take their medication and giving them something to eat. In other visits observed with the same client, the homecare worker would spend more time with the client, involving them in meal preparation decisions and engaging in conversation whilst watching a quiz show on TV together.
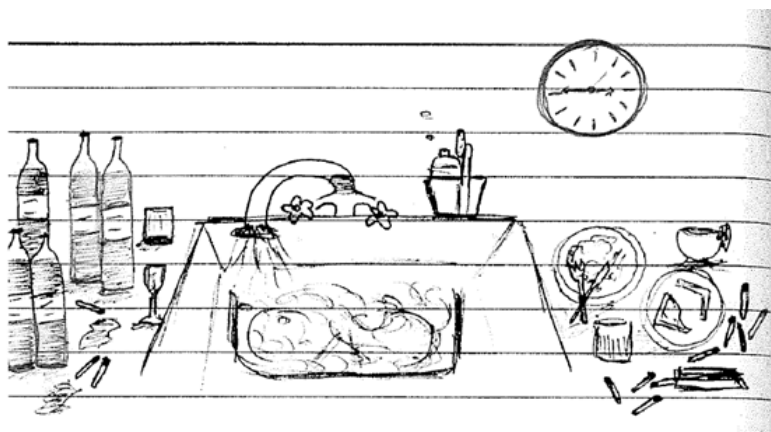

Figure 6.2: Observation sketch of a client's kitchen sink area

6.1.3   Theme three: Independence and empowerment

In this final theme, I explore how independence for clients living with dementia could be supported by homecare workers ensuring their client's voice was heard in relation to how care was delivered. Often decisions made on behalf of the person living with

dementia were necessary, however, who made those decisions and whether they represented the client's voice could be challenging for homecare workers to navigate. This sometimes resulted in feelings of powerlessness against decision-making authorities, particularly when homecare workers did not feel the decision was made in the best interest of their client.

When homecare workers, family carers and the person living with dementia felt they were working in collaboration, the experience was perceived positively, particularly in strengthening the voice of the person living with dementia:

'It's a three-way street… Between the carer, the client and the family. As long as the family is wanting to put the input in, that in turn helps us, which then in turn allows us to do that bit extra for our client.' (Homecare Worker 17)

'I think there's something about making sure the person with dementia has a voice, and not talking for them, even if their voice sometimes is very muddled.' (Health & Social Care Professional 17)

Most clients observed were not able to make all their own decisions about care. Many decisions were made by others, often family carers who became a proxy or substitute for the voice of the person living with dementia. Homecare workers often felt unsure of how to challenge or question proxy-decisions with which they disagreed, because while privileging the client's voice might be construed as supporting their independence, it could also be seen as directly challenging of the family carer's authority:

'I know you've got to respect the families' choices as well, but I think the client's choices are important and I think you've just got to do things for the better of the client for what is going to be more beneficial to them.' (Homecare Worker 20)

In the example below, we observed a visit where the homecare workers were asked to contravene the wishes of the person living with dementia; judged to be in the best interest of the client:

The homecare workers agreed to try to move Beth into her chair, and when it came to using the hoist after getting her washed and dressed in bed, I observed that Beth was calm and relaxed in this time, talking to the homecare workers about what she could see out of the window. In another example, the homecare workers made a decision against the request of the family carer, perceived as being in the best interest of the client:

‘When removing Beverly's pyjama bottoms, Abbey tells Ashley that her pad is causing red marks and is rubbing on her skin, but that Beverly's husband had asked them put one on her. Abbey is not happy with this decision and Ashley listens to her concerns and agrees. They decide together that they will take it off.' (Agency 2)

In the previous chapter, I considered the positioning of homecare workers as a proxy-care professional, yet it could be difficult for homecare workers to navigate amongst family carers and care professionals who have an accepted place in decision-making. Carrying out proxy-decisions could be particularly difficult if there was a disagreement amongst decision-makers about what was judged to be in the client's best interest.

There seemed a fine line for homecare workers between providing support with 'a bit of diplomacy' (Homecare Worker 23) and stepping out of place with family carers. One homecare worker who was observed taking on excessive responsibilities for her client at the request of family carers, was later asked to leave by the family for taking a smoking break outside whilst working overtime, waiting for the client's new dishwasher to arrive:

‘Angela tells me that she is no longer working with Betty as Cliff had accused her of some wrongdoing in Betty's home. Angela can no longer see Betty and must not

> return to her house to say goodbye; she is upset and concerned for Betty as she didn't have a chance to tell her she wouldn't be coming back.' (Agency 1)

Though we only heard one perspective on this decision, the sudden dismissal 'after providing such committed care to Betty for over two years', illustrates the insecurity of the homecare worker role. Other homecare workers also acknowledged feeling powerless against those who made the decisions and were ultimately in control over their client's living situation:

> 'Anna says that she fears Beatrice will not have the strength to hold herself up or walk after being in bed for one week. She says that the social services' decision to keep Beatrice in bed has "completely taken everything away from her" and feels there is nothing they as homecare workers can do about it.' (Agency 4)

Homecare workers may be well positioned to advocate for their clients living with dementia, yet their ability to do so may be hindered by the power dynamics involved in homecare and the insecure position of homecare workers within the client's multidisciplinary care. This, in addition to the vulnerability of the role, may be a source of stress for homecare workers when they wish to advocate for what they believe to be in their client's best interest.

6.2 Summary

In this chapter, I have explored how homecare workers supported or inhibited independence in their clients living with dementia. I highlighted how the home environment as a site of care required homecare workers and clients to negotiate the available space, balancing familiarity, the client's independence and ownership of their home space, and risk to both homecare workers and clients. My findings highlighted that without a regular place of work, clients' homes by extension were often used by homecare workers as a quasi-workplace. This could blur boundaries, depersonalise and overshadow the familiarity of the client's home, and thus the connection of the home with the client's identity, personhood and independence.

I explored how homecare workers were able to support independence in clients living with dementia by acknowledging and understanding their present identity and functional abilities, involving them in tasks and activities, and offering meaningful choices. However, this was more challenging with short visit times and with clients living with more severe dementia. I considered how homecare workers working collaboratively with their clients living with dementia and their family carers enabled them to contribute to everyday decision-making. In observations, homecare workers were not usually included in key decisions about their clients' care, and when they disagreed with decisions, this could sit uncomfortably if they felt the client's wishes had not been sufficiently considered.

Through their familiarity with and understanding of their clients living with dementia, I considered homecare workers to be well-positioned to advocate for their client's voice in decision-making around care. However, representing the client's best interest and navigating amongst proxy-decision makers could be frustrating, sometimes resulting in homecare workers feeling powerless or wanting to challenge decisions they disagreed with on behalf of clients. From my observations, their exclusion from both decision-making and explanations about why decisions were made, increased the tensions around this.

In the next chapter, I will discuss my personal reflections as an ethnographic observer, considering my potential impact on the data I collected and subsequent findings.

Chapter 7   Reflections as an ethnographic researcher

Reflexivity in qualitative research is considered 'crucial cognitive practice' (Mortari, 2015) and a foundation of ethnographic fieldwork (Emerson et al., 2011). In this chapter, I will discuss my personal reflections that emerged during the ethnographic data collection presented in this thesis. I will structure my reflections in relation to two pertinent concepts: Trust and Truth. This can be applied to qualitative interviews concerning what I was told by participants, and the participant observations regarding what I saw happening.

My reflective process involved acknowledging elements of my personal background, assumptions and presumptions in considering the influence of my own biases on the research (Reeves et al., 2008) (presented in Figure 7.1). Whilst several researchers were involved in data collection, I will present my own perspectives, experiences and assumptions only. Part of this chapter comprises a 'think-piece' which I developed for a workshop run by the UCL Qualitative Health Research Network on 'Truth, Trust and Research in Health and Social Care' [Appendix 20].

Figure 7.1: Elements of my background and personal impact upon the research

7.1 Gaining trust as an outsider

Ethnographic methods, particularly participant observations, require the researcher to become immersed in the field. While qualitative interviews can be guided or structured, there is no standardised observation method and variations exist in the extent to which the observer engages with the population of interest (i.e. their level of 'participation') as well as how they enter into the observer relationship. For example, the observer may have a dual role as both a nurse and a researcher observing in a clinical setting; with the benefit of pre-established familiarity in the field and trust with participants (Watts, 2011). Wearing a uniform, such as that worn by a nurse whilst in the field, can serve to quickly establish trust as an insider, yet poses ethical concern regarding potential manipulation of participants when wearing a uniform whilst in the role of observer (Strudwick, 2019).

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For researchers entering the field as an outside observer (i.e. no previous connection with the population or setting of interest), prolonged participation may be necessary to develop trust. However, ethnographic research within health and social care seldom have the luxury of time, with rapid approaches being adopted to respond to more immediate challenges (Vindrola-Padros & Vindrola-Padros, 2018); hence prolonged participation is rarely possible. The outside observer must find other ways to develop familiarity and build trusting relationships with their participants.

'A successful participant-observer has to inspire enough trust and acceptance to enable her research participants to act much as they would if the researcher were not present' (Guest, Namey, & Mitchell, 2013, p. 3). Conducting qualitative interviews helped me build rapport and familiarity with some participants prior to observing them. However, my methodological design also intended to observe different participants to those who were interviewed, to provide greater sample diversity and understanding of my participant groups.

Observing care in the home has greater methodological complexities than care provided in hospital or residential settings where most ethnographic healthcare research has taken place. Gaining the trust of the participants was necessary to capture a more authentic representation of care provision for people living with dementia at home, and the trusting relationships that formed between participants.

Transitioning from an outsider to the inside requires skilled negotiation to establish and maintain rapport (Pitts & Miller-Day, 2007). I aimed to foster rapport by incorporating familiarisation visits into my methodological design, before the main observations began. In these visits, I observed without taking any fieldnotes with the aim of enabling participants to become familiar with having a researcher present and to normalise the experience of care provision/receipt being observed by an outsider. In these visits, I heard from some homecare workers about their initial concerns around my presence and their work being scrutinised. Considering my finding around perceived power dynamics presented in the previous chapter, I wanted to ensure that I did not abuse my position of power as an observer, given the vulnerability of the homecare role and wider surveillance and scrutiny surrounding homecare. Clients and family carers too voiced their concerns, notably around their "favourite"

homecare worker being "taken away" if the observations portrayed them in a negative light.

I sought to manage these concerns by reminding participants that the purpose of the observations was to explore homecare for people living with dementia as it occurs in practice, rather than to make judgements on the quality of care, in which I was not positioned nor trained to do. However, I was clear about my ethical duty to report abusive behaviour or where any persons involved were deemed to be at risk of harm or neglect. When such situations arose, I reflected upon feeling guilt for 'whistleblowing' on people with whom I had developed trusting relationships. For example, I reported concerns to an agency manager when a homecare worker revealed the home address of another client in front of her current client's family member, and where a homecare worker took down a client's fire alarm without replacing it, because she found its beeping frustrating.

Beyond the familiarisation visits, I continued to build trust and rapport throughout my time spent with homecare workers and their clients, as well as in interactions with homecare managers. Some homecare workers and clients seemed comfortable with me simply sitting and watching, while others wanted to engage and get to know me personally. In one situation during the recruitment process, I was warned by a client's family member (the nominated consultee) that the client did not take well to strangers and probably would not want me in her house. During the first familiarisation visit with this client, her homecare worker introduced me as a student which was proceeded by the client signalling for me to sit beside her. She spent the next 30-minutes of the visit holding my hand and asking questions about my work. The homecare worker thought the client had taken a liking to me because she used to be a nurse and had regularly trained students of her own. It was for this reason also, that the family member provided consent for their relative's participation in the study, as they believed it was what she would have wanted, given her background as a nurse.

Reflecting back on this visit, I wondered how these observations might have differed if I had not been introduced as a student, but as a researcher; being known to participants as a researcher has been suggested to delay the process of rapport

building (Guest et al., 2013). Reflecting on this situation personally, in other situations I would have felt uncomfortable in holding the hand of a stranger. Yet, in this situation, it likened to many similar situations holding my grandmother's hand, particularly in the years she lived with dementia. Familiarity and empathy displaced my discomfort.

Likewise, it was necessary to establish trusting relationships with the homecare agency managers. When recruiting homecare staff for the interviews, contact with the agency manager was often brief and limited to one or two meetings or phone conversations. More contact was required with agency managers during the observation period. I spent more time collecting data in one agency in particular, where I was invited by the homecare manager from the start to sit in the agency office during breaks; this was one of the offices with a communal space, as I described in Chapter 5. After several visits to the office, a senior office staff member offered to show me around the local area on her lunch break. In this time, the staff member asked me many questions about myself and the purpose of my research. I explained I was motivated through personal positive experience of a relative receiving homecare. Revealing this seemed to be the pivotal point in securing my position as an insider, albeit as a guest, and facilitated a more trusting relationship within the agency. In this agency, the manager was initially only selecting the "best" care workers to be observed. Once trust was established, I was able to observe homecare workers who were new to the work and had yet to complete their training, and those whose motivations to provide care were described as a "stepping-stone" to a more desired career path. I reflected upon situations such as these, as the need for the observer to share parts of the self to gain the trust of those being observed.

7.2 Truth

I considered the concept of truth in several forms. Firstly, my ability as a researcher to capture 'truthfulness' in the narratives and behaviours of participants. Secondly, my ability to see and report truth amidst my own pre-considered biases and background. Lastly, I considered the concept of truth-telling with people living with

dementia who experience memory loss, or in contrast, deception and its potential impact on independence and dignity.

7.2.1 Capturing truthfulness from participants

Capturing truthful or genuine behaviours from participants stems, in part, from gaining their trust. When interviewing participants, there is typically a single shot at capturing their truth. This may largely depend upon the skill and sensitivity of the interviewer in creating a safe space in which participants feel comfortable in sharing their experiences. Upholding ethical rigour will also help this, ensuring participants know that the interview is confidential, and that anonymity means they cannot be identified. An initial phone conversation with participants helped to some extent, in establishing familiarity with participants, giving time to answer their questions. Before the interview began, I engaged in light conversation with participants in addition to reminding them of the purpose of the research. I found this particularly helpful when interviewing people living with dementia in creating a relaxed atmosphere. Cues of reassurance felt important when interviewing family carers and homecare staff. Some participants in these groups expressed relief in being able to openly talk about their experiences which often involved venting frustrations. One homecare worker emailed me after her interview to say she had felt "heard and happy". To me this signified unveiling of truth and authenticity.

With the observations, as mentioned above, I included familiarisation visits into the design of the participant observations to allow time to build rapport and gain trust, which in return, could facilitate participants to behave as they would without my presence. I noted in my reflective journal early on that "familiarisation seemed to become familiar quicker than I expected". While I planned to carry out up to two familiarisation visits with each homecare worker per client, some homecare workers reported feeling comfortable with me taking observation fieldnotes after just one familiarisation visit. Upon reflection of why this occurred, I noted that asking questions and using ethno-interview techniques during these visits, rather than shadowing the homecare worker in silence, fostered familiarity and may have facilitated open and reciprocal communication between myself and the homecare workers. At the end of the first visit, some homecare workers discussed elements of

their personal lives with me, and voiced frustrations with their employer. One homecare worker described feeling that we would be "great friends" by the end of the research. I considered my age and personality as contributing factors, and perhaps even my appearance; at the end of an interview, a homecare manager described me as "cute", thinking this would help me to recruit homecare workers to observe as they would be less "intimidated".

In other situations, my presence as an observer may have directly altered the behaviour of the homecare worker and/or person living with dementia. One pertinent example of this was a scenario I presented in Chapter 5, where the homecare worker, Alison, felt anxious when visiting a client whom she believed did not like her, and described her as often being verbally abusive. However, I did not observe this during my observations, instead perceiving the client as friendly and warm. Alison commented on the client being more "tolerable" when I was present and expressed concern about visiting the client alone once my observations ended. I considered how this reaction suggested that Alison may not have felt safe visiting this client alone, particularly when her reports of concern to the agency manager appeared unheeded.

In reflecting upon my impact in this scenario, I thought back to the familiarisation visit with this client, where she asked me to sit close to her and took an interest in my hair – she had been a hairdresser all her life. Later on, in the same visit, I noted that the client described the meal Alison had made for her as "lovely", whereas she had reportedly referred to the same meal as "slop" in Alison's previous visit. I discussed the client's change in behaviour with Alison after each visit. Both she and I expressed feeling the client had taken a liking to me partly because of my age and appearance (I had long hair, whilst Alison's was short), and considered whether me spending time talking with her during the familiarisation visit facilitated this as the client enjoyed socialising; Alison had described the client as being very lonely on numerous occasions. However, Alison's previous bad experiences with this client, as well as lack of time, prevented her from spending time providing companionship during visits. I found it interesting to observe that by the end of my final visit, Alison's attitude towards the client also seemed to change and had become more positive,

mirroring the client's behaviour which was warm, friendly, and upbeat during the visits I observed.

I reflected upon the potential interventive effect of my presence as an observer and use of ethno-interviewing, in encouraging the homecare worker to perhaps also take an observational stance and consider what was happening during these visits. When considering whether my presence altered my ability as an observer to capture genuine or truthful interactions in these visits, it is useful to consider the epistemological stance of post-positivist critical realism with which I approached the data, that there is no singular reality or truth (Bhaskar, 1978); rather human behaviour is changeable upon the contexts in which it is observed.

7.2.2 Seeing truthfulness as an observer

In reflecting upon whether it is plausible for an observer to see 'truth' in ethnography, one can consider Hammersley's (1992) notion that 'there is not a single valid description of a situation'. Therefore, this leads one to question - *if another had been there, would they have seen what I saw?*

I considered how my personal experience of homecare for my grandmother who lived with dementia may have impacted what I saw and heard from participants, and how I narrated these in my fieldnotes. My motivation for embarking on this PhD was the positive experience of homecare my grandmother and our family had received for many years. As I discussed in the introduction of this thesis, homecare workers and the homecare sector face much scrutiny from the media and the public. My own experience of homecare was not congruent with this negative perception and I wanted to shed light on the positivity and the value of the sector, particularly for people living with dementia.

I recognise that in my findings I have largely presented positive examples from my data collection, which was perhaps influenced by my own predisposed biases and motivations for the research. Collecting data as a team, rather than as a lone researcher, helped to mediate these biases by bringing in multiple perspectives to approach both the data collection and interpretation. I also sought to counter any bias by searching for examples that were dissonant to the prevailing positive

narrative. These included situations that were concerning to the researcher-observers (such as when medication was found stored down the side of a client's chair), where relationships in the homecare scenario were experienced as challenging, and the difficulties homecare workers faced that confronted their own wellbeing.

When considering where my own biases may have skewed the tone of my observation fieldnotes, one particular example from an early observation stands out to me. I had conducted two familiarisation visits with a homecare worker whose client living with dementia also had deteriorating mobility, as a result of which the homecare worker had reported difficulty in supporting the client around her home. In my next visit, the homecare worker informed me that a decision had been made between social services and the client's family to keep the client in bed from then on. The homecare worker did not agree with this decision and described it as "taking everything away" from the client. I found myself agreeing with the homecare worker, which at the time, subconsciously introduced a negative tone represented throughout my fieldnote narrative; using the terms "bed-bound" and "confined to bed" in describing a situation where I felt frustration with and anger towards a voice, or group of voices (i.e. the client's multidisciplinary care team), I had neither met nor spoken to, to understand the situation from their perspective.

Throughout my analysis, there was a natural tone of empathy towards a workforce and client group portrayed as vulnerable and powerless. By predominantly observing these participant groups, they were the voices I heard the loudest and are therefore reflected most strongly throughout my analysis. Had I spent more time alongside other stakeholders during the observations, my lens may have altered. I believe it important to consider here, the power disparities and inequalities between myself as a researcher and the participants, in terms of level of education, social class and potential life trajectory. The notion that 'the researcher is more powerful than the researched' is well established (Riley, Schouten, & Cahill, 2003) (although this is being challenged in practice through the use of more participant-led research). Rather than viewing this disparity in research as exploitative, it can also be re-framed as a means to empower: with a higher societal position, researchers have a responsibility to use

their power to advocate for, and empower the voice of their participants. By integrating participants' perspectives through interviews and becoming embedded within the homes and workplaces of the participants during observations (particularly those whose experiences were not captured in interviews because they lacked capacity), we gave a voice to the lived experiences of the homecare workers and people living with dementia.

Awareness of the impact of my own biases in seeing and reporting truth was an iterative process and one that was helped by regular meetings with my PhD supervisors to discuss my observations. Engaging in reflective practice aided recognition of such biases, from which I sought to maintain a neutral stance in my observations going forward. Iteratively analysing and discussing the data with the other researcher-observers (AB and JBD), as well as the wider study team which comprised of different backgrounds and viewpoints, further helped to negate the weight of my biases alone; a technique termed 'fair dealing' by Mays and Pope (2000). Presenting extensive example quotes from different participant perspectives and a wide range of fieldnotes that were both in compliment and contrast, particularly between stories lived and stories told, also served to impart support and rigour to my analysis.

7.2.3   Truth-telling with people living with dementia

'Therapeutic lying' is often deemed acceptable when in the client's best interest (Elvish, James, & Milne, 2010). I heard about and observed this across family carers, homecare workers and health and social care professionals, where the truth was withheld from clients if the reality would cause upset or pain, such as when clients asked where a deceased relative was. In one situation I observed, a family carer wanted to withhold the client's dementia diagnosis from them to prevent further confusion, which the homecare worker agreed to uphold. By extension, I was asked to make the same agreement as someone entering into their home. I felt uncomfortable going along with this, but understood why the decision had been made and respected the family carer's wishes after discussion with the homecare worker and manager. Ultimately, I hoped a situation would not occur where I overtly had to lie to the client; luckily it never did.

Although the concept of truth-telling with people living with dementia has been explored retrospectively through survey and interview data, participant observations enabled me to capture the complex reality of truth-telling in the context of care provision for people living with dementia at home, with homecare workers having to negotiate this moral and relational complexity. Reflecting upon this as someone with personal experience of caring for a person living with dementia, I often found kindness, rather than dismay, in situations where homecare workers chose to spare the client upset by withholding the truth, if the truth was perceived to be painful. I presented an example in my findings when exploring the relational components of homecare, where a homecare worker had brought flowers for her client. During the visit, the client commented on the flowers admiringly, saying that her mother had bought them for her; the homecare worker never corrected her, but joined in conversation admiring the flowers.

7.3   Summary

In this chapter, I have discussed my personal reflections that emerged throughout the ethnographic study and considered how my predisposed biases may have unintentionally impacted the research. I focused my reflections across two key concepts - truth and trust - considering these in relation to the narratives and behaviours of participants involved in the study, and in how I heard and observed situations as a researcher. I processed these reflections and developed my analysis in parallel, drawing on the support of my supervisors and the wider NIDUS research team; adopting the process of 'fair dealing' (Mays & Pope, 2000) with which to view and identify the resulting findings.

In the next chapter, I describe how I integrated findings from my ethnographic study to inform the coproduction of the NIDUS-Professional training intervention.

Chapter 8   Informing the NIDUS-Professional training intervention

This chapter responds to the final objective of my ethnographic study: to integrate findings from my PhD research to inform the coproduction of the NIDUS-Professional training and support intervention. Inherent to my ethnographic work were the dual aims of contributing more broadly to understanding and developing knowledge in the field of homecare for people living with dementia, as well as contributing to product development – a training and support intervention for the homecare sector. The focused nature of my ethnographic work, in particular, was planned to inform the NIDUS coproduction process and around the need to develop an evidence-based intervention in a timely manner; responding to the pressing needs of the homecare sector and calls from policy makers for better training for the workforce and its care for people living with dementia (Carter, 2016b; Department of Health, 2015b).

In this chapter I describe how my findings informed the coproduced NIDUS-Professional training and support intervention. I will begin by discussing the coproduction process and my role in informing it. I will then outline the NIDUS-Professional intervention, describing and illustrating how my findings were implemented in the manualised intervention.

8.1   Coproduction in research

Coproduction is a collaborative process between stakeholders, with particular focus on developing a partnership between researchers and individuals from the public or organisations who can represent the needs and experiences of society (Hickey, 2018). By involving lay persons as active collaborators, coproduction has the potential to improve and evolve research (Stephens & Staniszewska, 2015). There is no one agreed method for coproducing interventions, but it should involve 'active engagement' and not just consultation, power sharing, respect of different skills, perspectives and experiences, and overall reflection of the coproduction process (Hickey, 2018).

8.1.1 Collaborating with people living with dementia

Services and interventions developed for and in collaboration with people living with dementia may be of greater quality and relevance to their needs (Gove et al., 2018). While people living with dementia are more frequently becoming involved in these collaborative roles, challenges to meaningful coproduction with people living with dementia exist and can occur when researchers adopt a dominant, patronising or paternalistic stance (Gove et al., 2018). Working with people living with dementia as collaborators requires the use of accessible formats of working as a prerequisite to meaningful coproduction. This may enable the continued participation of individuals living with dementia experiencing further cognitive decline, particularly over the course of longer studies (Gove et al., 2018). However, few attempts at coproduction have sought to include people living with severe or advanced dementia (Burton, Ogden, & Cooper, 2019).

The Scottish Dementia Working Group Research Group (2014) developed guidelines based on core principles for involving people living with dementia in research. This emphasised the importance for people living with dementia to be involved in driving research priorities based on their experiences, and not just as consultants on researcher-led topics. It also outlined that people living with dementia should be valued as collaborators and kept informed of the research and its progress, and enabled to contribute in a safe and secure environment, with simple and respectful communication about the research, and for all collaborators to be 'dementia aware' (i.e. compassionate) and mindful of 'dementia time' (i.e. making time for breaks) (Scottish Dementia Working Group Research Sub-Group, 2014, pp. 683-684).

8.1.2 Collaborating with homecare staff

Coproduction seeks to change the power balance between researchers and non-academic collaborators by situating the former as facilitators and the latter as experts (Boyle, Clarke, & Burns, 2006). In the context of social support such as homecare services, frontline staff are crucial to the quality of service delivery (Realpe & Wallace, 2010), yet are rarely involved in the process of service development. Involving key stakeholders in research facilitates the translation of research into practice and may

in turn, increase the trust and confidence of end-users (Hunn, 2013; Laird et al., 2020). Thus, the involvement of homecare staff in a training intervention for homecare workers may promote trust and confidence in the training material. Guidance such as the approach to research prioritisation adopted by the James Lind Alliance (JLA) (2020), supports meaningful collaboration with frontline care staff as equal partners in developing research.

Working in a research setting may be a new experience for collaborators involved in service provision, such as homecare staff, who are not used to being in such a position. Ensuring a comfortable, secure and neutral setting, with accessible documentation and information sharing may ease some concerns. Particular challenges may arise such as disagreements between collaborators from different organisations, particularly if from competing organisations. This was the case in a coproduction project facilitated by Ottmann and colleagues (2011), where group dynamics were reported to be complex because of 'differentials of power and authority' (p.3). Strategies to remedy this situation involved splitting the group into two smaller groups, having an experienced facilitator, and creating greater focus to the meetings that allowed less room for deviation in the allocated time (Ottmann et al., 2011).

8.2   The process for coproducing NIDUS-Professional

NIDUS-Professional involved four coproduction workshops that took place at the University of Bradford and UCL, between September 2019 and February 2020. The coproduction group included members of the public and service providers with experience of providing or using homecare services. We invited homecare managers, homecare workers, people living with dementia, and unpaid carers for a friend or relative living with dementia in the community, to work together in developing the training and support programme for homecare workers. The workshops were facilitated by researchers from the NIDUS study team.

Coproducing the NIDUS-Professional intervention comprised three key elements (as outlined in Figure 8.1): 1) An evidence-base derived from systematic reviews of the literature on interventions for homecare staff supporting people living with dementia

(Cooper et al., 2017; Goh et al., 2018) and other relevant interventions (Low et al., 2015; Polacsek et al., 2020; Rapaport et al., 2020a); 2) The lived experience of the NIDUS coproduction group; 3) Case-based learning centred on my research findings (presented in Chapter 5 and Chapter 6).
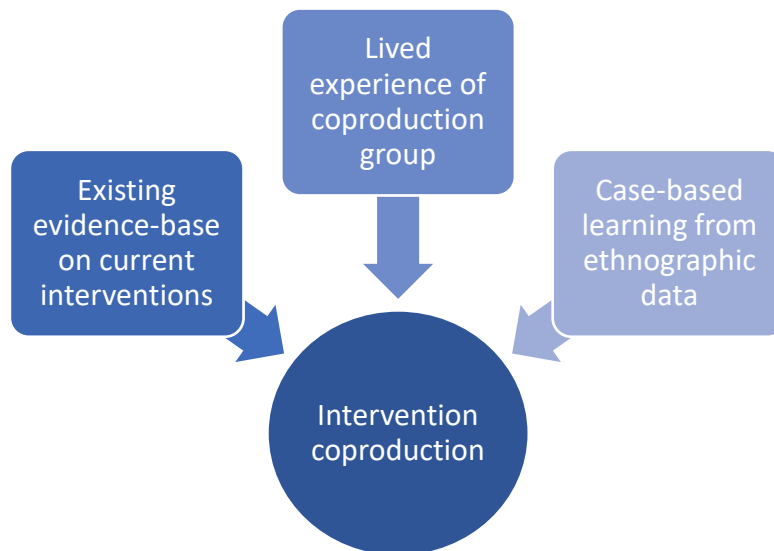
Figure 8.1: Key components of the NIDUS-Professional intervention coproduction process

8.3 The NIDUS-Professional training and support intervention

The format and content for the NIDUS-Professional training and support intervention were collaboratively developed over the course of the coproduction workshops. The intervention is delivered to homecare staff within participating agencies (different to those involved in my ethnographic study) in small groups, over six training sessions, each lasting 1.5-hours, held either weekly or fortnightly. The training sessions are manualised; facilitators have an annotated version of the manuals, which they interactively work through with homecare staff who have non-annotated manuals. The intervention was originally planned to be face-to-face but was adapted to be delivered digitally via Zoom video application, in light of the COVID-19 pandemic. The pilot group ran from November to December 2020, of which the findings are reported in Lord et al. (submitted).

8.4 How my findings informed the coproduction process and intervention development

Before the coproduction workshops, I attended two homecare training courses as experiential learning. One course was a private homecare agency's in-house induction 'This is Dementia' training session, developed in collaboration with the Alzheimer's Society Dementia Friends' initiative. The second was an external course developed and taught by the UK Home Care Association (UKHCA). Situating myself in the position of a homecare worker attending these training sessions helped me understand how training for homecare staff is currently run and to develop a sense of what works well in practice from the perspective of an attendee.

In the NIDUS coproduction workshops, I presented my ethnographic findings (reported in Chapter 5 and Chapter 6) in accessible formats that were reviewed and discussed in small groups. I included a wide range of anonymised quotes and fieldnotes from the interview and participant observation data, to illustrate each of the themes and subthemes, and open up discussion and reflections amongst the group. I included my photographs and sketches to talk about the findings in a visual and accessible way. The group discussed relatability of the quotes and considered how these examples might be used in the intervention and map on to the collaboratively decided training topics.

Across the four coproduction workshops, the group developed the manualised training and support programme, with each session focusing on a different learning topic. I have outlined each session and its content in relation to the themes of my research findings in Table 8.1.

Table 8.1: Mapping my findings to the NIDUS-Professional intervention sessions

Training session	Session title	Content	Mapped to theme from my findings
1	You and your role: How important it is to look after yourself as carers and ways to do this	Feeling valued in your role; getting support and supporting yourself; looking after yourself and managing stress	Chapter 5 - Theme one: Navigating the homecare role and identity Chapter 5 - Theme four: Agency and team support
2	Building positive relationships: Getting to know your clients and communicating with them	Getting to know your clients and building positive relationships; understanding how it feels to live with dementia	Chapter 5 - Theme two: Developing and utilising relational and emotional skills Chapter 6 - Theme two: Independence and identity
3	Understanding behaviour as communication	Communication and understanding behaviour	Chapter 5 - Theme three: Managing risk, resistance and behaviours that challenge
4	Engaging your clients and trying new strategies	Supporting clients' dignity and independence; doing with your clients, not for them; finding ways to engage clients	Chapter 6 - Theme two: Independence and identity
5	BITE-sized activities and being a team	Planning activities with clients; working with family carers; working with other homecare workers and members of your team	Chapter 5 - Theme two: Developing and utilising relational and emotional skills Chapter 5 - Theme four: Agency and team support Chapter 6 - Theme three: Independence and empowerment
6	Bringing it all together	Summarising all sessions and taking knowledge forward	N/A

I selected supportive examples from my ethnographic data to include in the manuals. The selection of material was informed by the coproduction group who highlighted examples from the interview and observation data that aligned with the training topics, and finalised through discussions with the NIDUS research team. Together with my supervisors, I then created pieces of text, vignettes and role play activities from this material to use in the intervention manuals. I provide examples in Figures 8.2-8.4 of how my data was incorporated into the training manuals. Figure 8.2 is an example from the first session of the intervention, which used quotes to illustrate varied and difficult emotions associated with the homecare role.

Looking after yourself & managing stress

- Home care workers have told us how stressful the job can be.

- Common reactions to **stress** include feeling:

> *"I stood outside her door for 15 minutes, no answer. I could hear her phone ringing continuously inside. I thought the worst had happened"*

> *"There will be days when you just want to cry. You just take it as it comes, a minute at a time, that's the best way."*

> *"It would just be nice to know that somebody was there. It is quite strained mentally, really frustrating sometimes. Switching off from it, sometimes it is hard"*

Frightened — Worried — Low in mood — Frustrated — Tired — Irritated

- Caring for people with dementia can be physically and emotionally draining. Over time, stress can impact on your health and well-being.

- You can take steps to reduce the effect on you.

Figure 8.2: Session 1, page 9 of the NIDUS-Professional training intervention

Figure 8.3 is from the facilitator's manual of session four, on engaging clients living with dementia and trying new strategies. It uses a variation of an excerpt from my observation fieldnotes (also presented in Chapter 5) that captured an interaction between a homecare worker and her client living with dementia. I presented this observation in a coproduction workshop and it generated discussion amongst the group around strategies homecare workers can use to engage their clients in tasks to support their independence. In the training intervention, the facilitator and homecare worker will role play this interaction and then engage in group-discussion

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and reflection around what the homecare worker did well, what qualities they brought to the situation and if there was anything else the homecare worker might have tried in the same situation, drawing on their own skills and experience.

Role	Now let's read this example taken from a real-life visit – Angela is the carer and Betty the client with dementia – If I read Betty, would one of you like to volunteer to read Angela? *Background to the script: Angela is helping Betty to wash*
	Script
Angela	Alright Betty, we're going to give your hands and arms a bit of a wash now. Would you like to try and have a go?
Betty	I don't mind.
Angela	It might be good for you to have a try. Should we see how you get on and I'll be here to help if you need it?
Betty	I suppose it might be good for me.
Angela	That's great. Here's the flannel, it's already got some soap on it so start by giving your chest a wash [Angela gently touches Betty's chest]. Now your left shoulder… [Angela gently taps Betty's shoulder]. You're doing great Betty, now the other shoulder…
	Betty takes the flannel and uses it to wash most of her upper body
Betty	I don't mind if you do it now…
Angela	Okay you've done so well already. I'll just give your belly a wash then and we're almost done. You'll be nice and clean for the day.
Betty	Belly? I think you mean stomach! [Betty and Angela both laugh].
	Now let's think as a group about the questions in your manual:

- What did Angela do that worked well?
- What qualities did Angela bring to this situation?
- Is there anything else that you may have tried in this situation?

Figure 8.3: Session 4, page 3 of the NIDUS-Professional training intervention

Figure 8.4 is an example from the facilitator's version of session five of the NIDUS-Professional intervention, on communicating with other professionals and staff. The three case studies are anonymised adaptations of interactions captured in observations. These scenarios represented familiar challenges as discussed amongst the coproduction group and seek to encourage reflection during the training session on how they can be approached.

Communicating with other professionals and staff

It's great when you can work in a team with other home care workers, your manager, and family carers to support a client. But home care workers tell us it can be difficult when not everyone is on the same page. Here are some situations that home care workers have told us they found difficult. We're going to ask you to each look at one of these cases for a few minutes.

Case 1
- Chris told Angela that Betty said she didn't want to get out of bed today, so to leave her there. Angela looks at the care plan (she's not met her before) and it says to get her up.

Case 2
- Chris has installed a camera and set it up so Angela can monitor Betty through her phone app. Angela says that if she saw anything was wrong she would rush over.

Case 3
- Betty told Angela that she doesnt want her children there when she writes her will. Angela had to tell Betty's son that Betty wanted Angela to be there, and Angela actually witnessed her will.

How might Chris (family carer) feel?
    ………………………………………………………………………………….

How might Betty (client with dementia) feel?
……………………………………………………………………………………….

How might Angela (home care worker) feel?
……………………………………………………………………………………….

Figure 8.4: Session 5, page 6 of the NIDUS-Professional training intervention

8.5   Summary

In this chapter, I have responded to the third objective of my ethnographic study, integrating findings from the qualitative interview and participant observation data (presented in Chapter 5 and Chapter 6) to inform the coproduced NIDUS-Professional intervention - a manualised training and support programme for homecare workers who care for people living with dementia. Taking a focused, team-based

ethnographic approach to the research (as described in Chapter 4) enabled the timely production of rich and in-depth data, that informed the coproduction process of NIDUS-Professional.

In the next chapter, I will discuss the main findings and implications of this thesis, pertaining to research, policy and practice.

Chapter 9   Discussion

In this chapter I will summarise my findings in response to my thesis aims and objectives, beginning with my systematic review (Chapter 3), followed by an integrated view of my ethnographic findings (Chapter 5 and Chapter 6). I will then consider my findings in relation to the current evidence-base, and then within relevant theoretical paradigms, relating to the concepts of independence, active ageing, empowerment and feminism. I will consider the implications for dementia-specific training in practice and for policy in England. Lastly, I will discuss the strengths and limitations of this thesis and outline future directions for research in this area.

9.1   Summary of main findings

9.1.1   Phase one: Systematic review

The objectives of my systematic review were: 1) to describe the methodologies that have been used to observe how homecare was delivered to adults in the private setting of the home; 2) to explore how observation methods can inform researchers' understanding of quality of care delivered.

An initial scoping review highlighted few studies in this area exploring homecare for people living with dementia, so I widened my search to include studies observing adult clients requiring homecare for any reason. The included studies revealed the unique strengths of using observational methods to study homecare, capturing elements of care that other methods may not (Briggs et al., 2003).

In response to my first objective, I created a framework of key design considerations when planning participant observations. This included considering whether and how to collect fieldnotes as a team, and how to maintain consistency of fieldnotes and methods across researcher-observers. The review informed my decisions in developing the methods of the participant observations in my ethnographic study (phase two), including using a topic guide to aid consistency and asking the researcher-observers to take brief 'jottings' during visits and write notes up in full no more than 48-hours later to minimise errors in memory.

With regard to my second objective, I found that methods of observation elucidated well how care delivery compared with the definition I used of quality of care: 'care that was consistent, and enabled the development of trusting relationships between the homecare providers and recipients' (Cabana & Jee, 2004; Denton et al., 2015; Olsson & Ingvad, 2001; Saultz & Lochner, 2005). Observations allowed the timing, delivery and impact of care provision on clients, who many not otherwise be able to report their experiences, to be observed. These included when care was delivered without apparent time constraints, where the client's dignity was maintained and they were actively encouraged to participate in daily tasks which supported their independence, and where homecare workers became valued companions and confidants for their clients and relatives. The observations also revealed where homecare did not meet the standards of good quality care, which included homecare workers providing rushed care and appearing to lack sufficient training and support. The environment of the home was also observed as a hindrance in some care scenarios, where it was poorly suited for care delivery. I was able to explore many of these issues in more detail in my ethnographic study and considered how they specifically related to clients living with dementia.

9.1.2   Phase two: Ethnographic study – an integrated summary of findings

My ethnographic study involved conducting qualitative interviews and participant observations to explore two key research objectives: 1) to learn and understand from the experiences of homecare workers how they can be better trained and supported in their role'; 2) to explore how homecare workers can enable and/or inhibit independence at home for people living with dementia. The third objective looked at how to translate these findings to inform the NIDUS-Professional coproduction process (presented in Chapter 8).

I conducted two separate thematic analyses, responding to these objectives, yet they are undoubtedly interrelated; for example, how homecare workers support independence in their clients living with dementia depends, in part, on the training and support they receive. In this section, I discuss my findings in relation to these objectives, and describe what, collectively, they tell us about how homecare workers

deliver care that supports independence. I illustrate in Figure 9.1 how the themes around supporting independence in people living with dementia (orange boxes) and those relating to training and support needs of homecare workers (blue boxes) are interconnected. I have highlighted the two most prominent, overarching findings: the value of homecare relationships and the significance of the home. I discuss these in greater depth below.
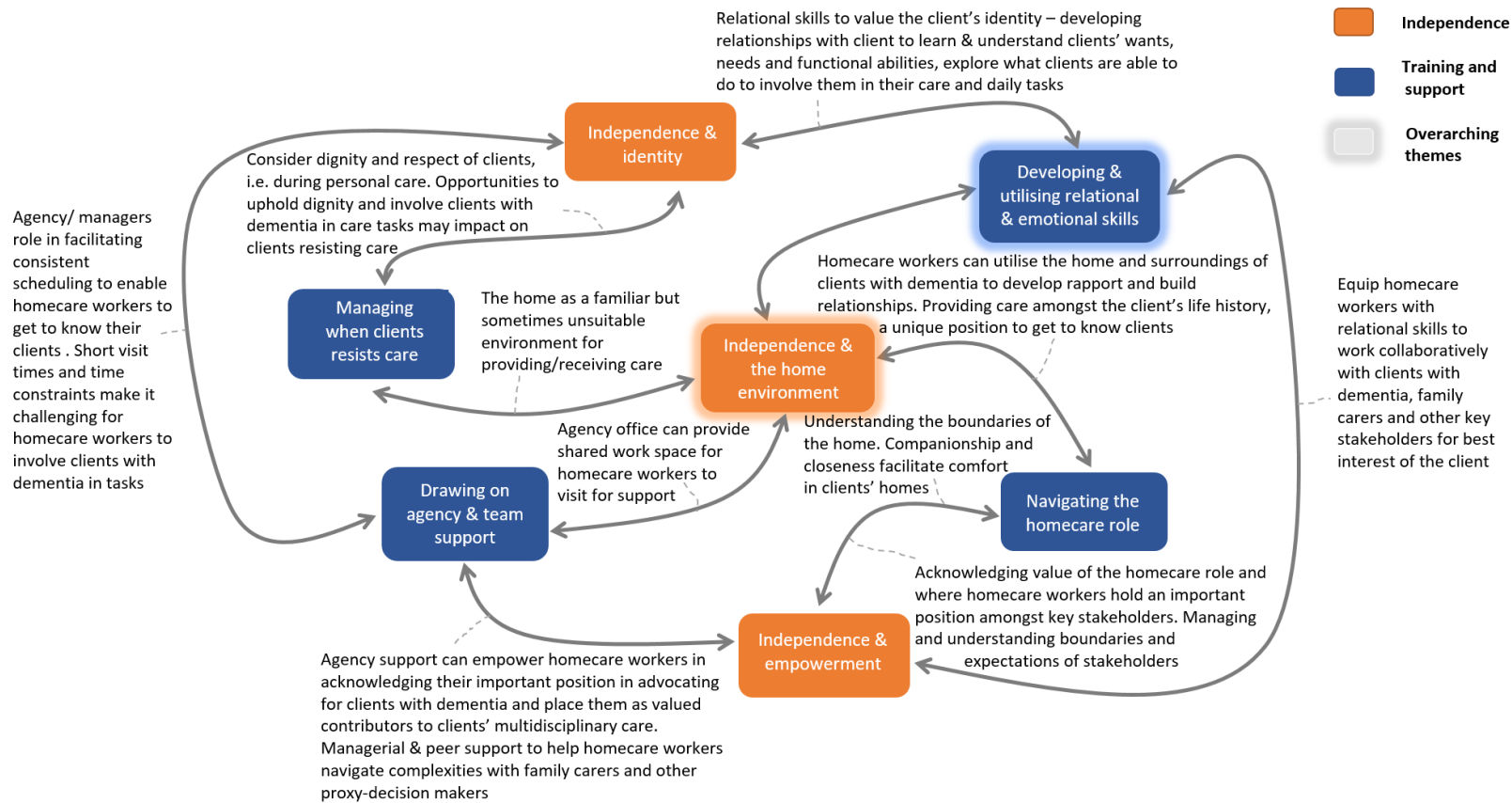
Figure 9.1: Theme integration illustration

9.1.2.1 Relationship-focused care

As identified in my exploration of homecare workers' training and support needs (Chapter 5), it was evidently important for homecare workers to develop relational and emotional skills to 'get to know' and understand their clients living with dementia; to 'speak their language', to value them as individuals, treat them with respect, and provide flexible, responsive, person-centred care, within the professional boundaries of the role. These skills were equally relevant to developing good relationships with family carers. This relationship-focused care theme was reflected in my findings on supporting independence (Chapter 6): relationships where homecare workers, family carers and the client living with dementia worked collaboratively, were perceived to uphold the client's voice (and thus some independence) in their care. Such relationships are akin to relationships of interdependence, where the client's support network facilitates their independence, as opposed to the notion that the client must carry out their daily tasks without support (Behuniak, 2010).

Close relationships facilitated familiarity and understanding of clients living with dementia; their likes, dislikes, needs and abilities. This knowledge enabled homecare workers to support their independence, by finding ways of involving people living with dementia in decision-making and daily tasks. However, time-constraints and the severity of symptoms in people living with more advanced dementia, limited the extent to which clients could be involved. I observed, for example, how homecare workers struggled to enable several clients with more advanced dementia to make meaningful choices. There was an apparent disconnect between what participants said in interviews, where a person-centred care approach was consistently aspired to, and our observations, where this was more challenging to achieve in practice.

The development of close relationships between homecare workers and their clients living with dementia was valued and expected; yet there seemed sometimes a thin line between this and excessive emotional involvement. There was a sense that it was up to individual homecare workers to navigate often close and complex relationships with clients living with dementia and their family members.

9.1.2.1.1 The importance of identity

To support the independence of people living with dementia, homecare workers needed to understand their client's identity: who they were before developing dementia, and who they remain to be. I reflected on how this mirrors the ambiguities of the homecare worker role and identity. Homecare workers adopted a range of role identities, often in parallel, which sometimes brought conflicting expectations and challenging negotiations around their relationships. Although this offers similarities to the perspective of 'altercasting' as outlined in Chapter 1 (Kendall et al., 2019), I found that homecare workers were often positioned by others, rather than adopting these role identities to achieve a desired outcome in their clients.

At times, homecare workers were positioned to carry out tasks akin to a health or social care professional, yet the homecare role and status of the profession were perceived as undervalued, and the significance of their relationships with clients often felt unrecognised; homecare workers felt overlooked as important advocates for people living with dementia. Homecare workers reported feeling powerless in their role, and unsure of how and whether to advocate for their clients amongst proxy decision-makers.

9.1.2.2 The role of the home environment

Working within clients' homes, amongst their life memories and possessions, provided homecare workers with perspective and insight into their lives and identities, through enabling connections with the client's past and present; the attributes of their personhood (Kitwood, 1997a). This enabled homecare workers to see and respect their clients as individuals, beyond their dementia diagnosis, thus facilitating relationship development.

In some circumstances, there was an apparent tension in how adaptations and changes to the home could depersonalise, but could also enable quality care to clients who displayed behaviours that challenged or were distressed, particularly during personal care. It was important for homecare workers to provide safe and effective care to clients in these situations, yet homecare workers did not always feel confident

or supported to do so – by the agency, other homecare workers or indeed the environment of the home.

I reflected on the challenges of place for homecare workers. I described how the home transitioned into a hybrid space between the client's private, domestic space and the homecare worker's workplace. Without their own place of work, homecare workers used clients' homes as their own space which could be depersonalising for people living with dementia. While homecare was sometimes perceived as teamwork, it could also be isolating, with a lack of shared or independent space, and a lack of opportunity for emotional support, even after the death of a client. Where agency offices had a communal space, this was sometimes used by homecare workers as a place to visit during breaks and to seek informal support with peers and managers.

9.2 Interpretation of ethnographic findings in relation to current literature

In this section I consider how my ethnographic findings relate to existing literature. I firstly consider how my findings around the relationships between homecare workers, clients and family carers add to previous work, including the BOUGH project in England (Pollock et al., 2020; Schneider et al., 2019; Turner et al., 2018) and the PITCH programme in Australia (Polacsek et al., 2020); introduced in Chapter 1. I will then present my findings around the home environment in relation to other literature, considering the home as a site of care and as a workplace.

9.2.1 Developing relational skills and building relationships

9.2.1.1 Relationship development
The BOUGH project (Pollock et al., 2020; Schneider et al., 2019; Turner et al., 2018) used similar ethnographic methods to my research, to understand the scope and nature of good quality homecare for people living with dementia. From the perspective of family carers, companionship was identified as the most important feature of homecare (Pollock et al., 2020). Homecare workers highlighted the importance of good relationships (Schneider et al., 2019), described as those where mutual affectionate bonds developed between care providers and care recipients.

My findings relating to the training and support needs of homecare workers accord with this, demonstrating that homecare workers required the skills to get to know their clients as individuals beyond their dementia diagnosis.

I developed this idea further, by identifying the organisational processes and support that could be provided by the homecare agency to facilitate relationship development. For example, through consistent scheduling and matching homecare workers with clients (i.e. based on ethnicity, social and cultural values or similar interests). I found that homecare workers appreciation and understanding of their clients' ethnicity and culture were important for relationship development and could lead to clients dismissing their care worker if this was not achieved. Schneider et al. (2019) referred to this as emotional intelligence and suggested agencies develop care workers' skills of empathy where it is not possible to match homecare workers with clients, to achieve cultural alignment.

9.2.1.2 Collaborative working

The PITCH programme interviewed family carers and people living with dementia who were receiving homecare, to develop a programme promoting independence in dementia through quality homecare (Polacsek et al., 2020). Developing good working relationships was of central importance to care providers and recipients, as was collaborative working between homecare workers, people living with dementia and family carers.

My findings echoed some of the challenges to developing good relationships identified in the PITCH study, including discontinuity of care caused by organisational constraints; both our studies highlighted the inconvenience for family carers and confusion for people living with dementia when a new homecare worker arrived at a visit. Moreover, both studies identified challenges relating to lack of direct contact between homecare workers and family carers, and a mutual desire to have a direct and collaborative working relationship in supporting people living with dementia. The PITCH study reported this from the perspective of family carers, while I reported the same frustrations from homecare workers. For example, I presented a scenario where a homecare worker felt it was ineffective to go through the homecare agency

to inform a client's family member that the person had run out of food. This may be related to homecare workers often having a more direct and personal relationship with clients and family carers, than a professional relationship.

9.2.1.3 Impact of relationships on homecare workers

Homecare workers were often viewed as close friends or likened to a member of the family by clients and their family carers. As considered in Chapter 1, whilst this identity, termed the 'fictive kin' (Karner, 1998), was mutually enjoyed and valued by homecare staff and clients, it may have exacerbated the blurring of boundaries, detracting from the homecare worker as a professional, and placing greater personal responsibility on them as if they were truly a close companion. This is also likely to have been heightened by the intimate setting of the home environment, where some homecare workers' spent time socialising beyond their scheduled visits.

Close relationships and attachments to clients brought with them a greater sense of loss and grief when clients died. Homecare workers reported struggling to deal with grief/anticipated grief and not knowing where to get support from. The BOUGH project also reported that this was experienced as emotionally difficult, though homecare workers overcame the loss of clients and began working with other clients 'fairly easily' (Schneider et al., 2019). Other research aligns more closely with my findings, suggesting that homecare workers' experience of difficult emotions was often exacerbated by close relationships and insufficient support to prepare for the death of clients, in addition to having a heightened risk of grief (D'Astous et al., 2017; Van Riesenbeck, Boerner, Barooah, & Burack, 2015) and psychological burden (Devlin & McIlfatrick, 2010). I consider the emotional labour of care below [see section 9.3.3].

Despite these difficulties, relationship development is often stated as a primary benefit of care work and may therefore be a contributing factor to retaining homecare staff (Butler, 2009; D'Astous et al., 2017). Thus skills to build relationships have the potential to benefit homecare workers and the wider sector, as well as clients. Ben-Arie and Lecovich (2014) reported that clients with greater cognitive impairment had poorer communication and relationship quality with their homecare workers than clients with lesser or no cognitive impairment. I found that homecare

workers found it harder to meaningfully offer choice to people living with more advanced dementia, suggesting that training for homecare workers might benefit from a particular focus on communicating with people living with dementia who have greater impairments, to facilitate relationship development, and to acknowledge and explore these difficulties.

9.2.1.4 Relationships with family carers

I observed a delicate balance between homecare workers forming close relationships with family carers, and the risk of overstepping the mark if their advice was perceived to conflict with the family carer's knowledge or behaviour. As in my study, the BOUGH project reported close relationships between homecare workers and their clients' relatives, with homecare workers being described as part of the family (Pollock et al., 2020). Whilst we observed homecare workers giving tokens of affection to their clients and family carers (i.e. flowers), family carers in the BOUGH project reported giving gifts to their homecare workers, which to them signified that it was a 'genuine relationship' (Pollock et al., 2020).

As in my study, mutual collaboration between homecare workers and family carers was considered an important dimension of quality homecare by participants in the PITCH study (Polacsek et al., 2020). Family carers in the PITCH study wanted better communication procedures with their homecare workers; some took this into their own hands by adopting a 'message system', where agencies lacked their own approach to facilitate this connection. My findings also revealed frustrations from both homecare workers and family carers where there was a lack of direct contact, to the extent that one homecare worker we observed wanted to escalate her concerns to the local authority social services because of ineffective contact with the family carers. This reflects a mutual desire for direct and effective communication between homecare workers and family carers.

9.2.2 Homecare and the home environment

9.2.2.1 The home as a private space

I reflected on the home as an intimate, private space and the perceived need for homecare workers to enter the home as a guest, with dignity and respect. This

mirrors previous writings around the home as an extension of self (Dyck, Kontos, Angus, & McKeever, 2005) and symbolic of independence for people living with dementia (Førsund et al., 2018). Being enabled to remain living in their own home, surrounded by their possessions and life memories is, in itself, symbolic of independence. In a systematic meta-synthesis by Førsund et al. (2018) that included 45 studies involving 672 interviews with people living with dementia, the authors developed four main themes to explore the meaning of the lived space for people living with dementia. These were: belonging, meaningfulness, safety and security, and autonomy. Living at home was important to people living with dementia, as a place of belonging and familiarity, representative of both their history and continued independence. Living at home was seen as key to living a meaningful life with a diagnosis of dementia (Førsund et al., 2018).

9.2.2.2 The home as a site of care

I observed a paradox between the home as a place that represents independence for people living with dementia, and the transition into a less personal, hybrid environment when homecare is introduced. This resembles the ethnographic work of Dyck and colleagues (2005), exploring homecare for clients without dementia, in receipt of long-term care services. The authors considered how close relationships and mutual respect between care workers and their clients supported the negotiation of space, yet the reconstruction of the home as a landscape for caregiving was a source of tension, beyond the clients' control. Care recipients marked boundaries between their private space and the 'caring space'; for example, one client restricted the researchers' access to her bedroom (Dyck et al., 2005). In my ethnography, clients living with dementia did not restrict their home; rather their own access was restricted to minimise risk. This was sensed by some clients as a shrinking of their environment; one person living with dementia described feeling like 'a dog being locked out of its room'. This was echoed in Førsund and colleagues's meta-synthesis (2018), where the overarching theme was 'Living with dementia is like living in a space where the walls keep closing in'.

Other strategies to minimise risks for people living with dementia included making changes and adaptations to the home. In a qualitative study of homecare for people

living with dementia in Sweden (Sandberg, Borell, & Rosenberg, 2020), the authors described how homecare workers sought to reduce risks by removing carpets in the home, although they acknowledged that changes to prevent risk must be small enough so that clients are still able to recognise themselves in context; furthering the idea that the home is an extension of self. I similarly identified a need to balance supporting clients to maintain independence in the home, with protecting them from risks such as falls. This was illustrated where a client's deteriorated mobility led to a decision for her care to be provided in bed; yet the bedroom was not well adapted for care provision. Where decisions were taken to reduce risks in the home for people living with dementia, these had a particular impact on the client's independence and personhood, because the home was a key repository of personal memories and familiarity.

I perceived a moral tension, whereby homecare workers did not always agree with adaptations made to their clients' homes, yet acknowledged that they were necessary to keep the client safe. In previous qualitative studies, care staff experienced concordant feelings of conflict (Taylor & Donnelly, 2006), however the safety of homecare staff took precedence over clients' preferences (Glasdam et al., 2013; Swedberg et al., 2012, 2013); these studies were included in my systematic review (Chapter 3) where I highlighted that clients' homecare support could be withdrawn if they refused to accept sufficient changes to their homes in order to create safe working environments. This contrasts with my findings that homecare workers were sometimes at potential risk of injury when providing care to clients in unsuitable spaces. Glasdam et al. (2013) emphasised the need for homecare services to take into account both the choices of clients regarding their homes and the potential hazards for homecare staff.

To summarise this section, I have discussed the significance of relationship-focused homecare for people living with dementia. Developing and managing homecare relationships is a key dimension for homecare worker training and support, in addition to organisational practices that enable care continuity and collaborative working with family carers. I have also discussed the significance of the home as a site of independence and familiarity, and a link between the client's past and present

identity. Changes or adaptations made to the home to accommodate homecare may therefore be disorientating and depersonalising, yet sometimes necessary. This raises the question of who makes these decisions, adding to the evidence-base in support of the rights of people living with dementia to live well at home.

9.3 Situating findings within existing theoretical paradigms

In this section, I will relate my ethnographic findings to three relevant theoretical paradigms introduced in Chapter 1: 1) independence versus interdependence; 2) empowerment; 3) feminism and the emotional labour of care. Whilst discussed as individual theories, there is a common strand: that homecare workers and clients, if supported, can develop an interdependence that attains many of the ideals of independence, while acknowledging contexts of relationships and social connections, and the complexities of working at the interface of the personal and professional.

9.3.1 Reconceptualising independence: Independence versus interdependence

My work accords with previous work (Clotworthy, 2017; Rønning, 2002), situating homecare for people living with dementia as an interdependence, empowering home-living by enhancing support systems. As depicted in Kitwood's work (1997b) on personhood and person-centred care, and expanded upon in theories of relationship-focused care (i.e. Smebye & Kirkevold, 2013), acknowledging that all persons exist within the context of their relationships and social connections, rather than their own independent capabilities, lends support to the notion of interdependence in homecare. The concept of independence for people living with dementia can therefore be reconceptualised, moving away from the notion of independence as 'the ability to function in daily life with no or little help from others' (World Health Organisation, 2002), which, in reality, is a limited concept in its application to people living with dementia in receipt of homecare.

Interdependent relationships in homecare for people living with dementia may be associated with benefits such as prolonged functional abilities, decision-making and social connectedness (Keyes, Clarke, & Gibb, 2019; Rapaport et al., 2020a; Smebye, Kirkevold, & Engedal, 2012; Woods, 1999); and ultimately remaining at home for

longer. Striving for interdependence, rather than independence, therefore acknowledges the progressive reality of dementia, furthering the debate around 'active' and 'healthy' ageing (Higgs & Gilleard, 2016; Van Dyk, 2014). As dementia progresses, the ability to carry out ADLs will continue to decline, meaning that support from others, including family carers and/or homecare workers is often essential to support people to stay in a familiar environment in which their personhood is upheld, and with more opportunity to act with independence. Familiarity is important for people living with dementia, as we saw with the client who moved with his wife to a more accessible home, yet the lack of familiarity proved disabling.

9.3.2 Empowerment

Drawing on the theoretical work of Foucault (1984) as outlined in Chapter 1, my work has highlighted the somewhat paradoxical nature of power in homecare. Homecare workers are indeed in a position of power relative to their clients living with dementia, yet are also largely disempowered by organisational constraints and the wider care sector, as well as role identities that denigrate their professional status (i.e. the friend or 'fictive kin' role). In such scenarios, I found that identifying, or being identified as friend or companion, placed homecare workers in a position without the decision-making power that an actual family member has, while remaining responsible for the client.

In accordance with Hayward (1998)'s expansion of Foucault's work that posits power as both an enabler and inhibiter of possibilities for action, my work highlighted how the relationship-focused aspects of homecare could be empowering for both homecare workers and people living with dementia. Close relationships and familiarity with their clients, position homecare workers as important advocates for their clients amongst proxy decision-makers in their multidisciplinary care. I found that homecare workers can support and empower the voice of their clients living with dementia through their understanding of the client, their identity, personhood, and functional abilities.

9.3.2.1 Empowerment of homecare workers

My findings extend the current literature exploring the power dynamics of care staff for people living with dementia in care homes, NHS wards (Scales et al., 2017) and an Alzheimer's residential support facility (Kontos et al., 2011). Focusing on homecare, I have highlighted the important positionality of homecare workers through their familiarity with their clients living with dementia, yet their vulnerability and limited power within the context of the clients' multidisciplinary care. We observed homecare workers wanting to advocate for their clients, though they also described feeling powerless amongst proxy decision-makers. In one example, a homecare worker reported being dismissed by a family carer after two years of working with the client, for what the homecare worker understood to be the result of taking a smoking break during an extended visit whilst waiting for the client's dishwasher to arrive.

DeForge et al. (2017) considered class and gender as influential in shaping the power dynamics involved in dementia homecare; situating homecare workers in a 'low positional power' with which to negotiate and advocate for their clients. I consider below, how professionalisation of the workforce is a potential, yet widely debated solution to improve societal and professional status of the homecare workforce [see section 9.5.2.5].

My findings accord with the work on end of life care for people living with dementia by Manthorpe, Vandrevala, Abrams, and Samsi (2019), regarding the perceived vulnerability of homecare workers within the multidisciplinary care structure. The authors reported that homecare workers felt disempowered by more dominant clinical professionals who sometimes expected them to have medical knowledge or perform clinical tasks. I identified the importance of role clarity, in addition to the role of homecare managers in supporting homecare workers, by facilitating opportunities for peer and managerial support.

9.3.2.2 Empowerment of people living with dementia through active ageing

Discourses of active ageing present a more contemporary rhetoric around ageing, described as 'the process of optimising opportunities for health, participation and

security in order to enhance quality of life as people age' (World Health Organisation, 2002, p. 12). Yet, as discussed in Chapter 1, the challenges associated with ageing and dementia confront the notions of independence and active ageing.

Interdependence is positioned as playing an important role in active ageing, when considering people in their social context (World Health Organisation, 2002). The interdependence involved in homecare for people living with dementia acknowledges the importance of relationships and social connections in supporting active ageing. By building close relationships and getting to know their clients, their identity as an individual and their functional abilities, homecare workers can empower people living with dementia to partake in meaningful tasks and decisions, maintaining independence by remaining active and valued agents in their daily life; an important dimension in upholding personhood (Higgs & Gilleard, 2016; Kitwood & Bredin, 1992) and reaffirming self-identity (Hellström, Eriksson, & Sandberg, 2015).

This relates closely to the work of Clotworthy (2017, 2020) in her study of homecare for older adults (without dementia) in Denmark, and her conceptualisation of 'help to self-help': empowering people to take action in their lives and to live independently *with* support. My findings extend Clotworthy's message, specific to the care of people living with dementia: to empower people, it may be necessary to activate them via support, through a collaborative, responsive and relationship-focused care practice. Homecare has the potential to empower shared decision-making and shared responsibility, creating empowerment for care recipients and care workers.

9.3.2.2.1 Active ageing in people living with advanced dementia

The paradigm shift towards active ageing has attempted to alter societal narratives around ageing and dementia by minimising prejudices and highlighting older people's active contributions to society. Yet, there is a risk of overlooking the reality of functional decline and introducing oppressive ideals that devalue those who cannot attain them, including people living with dementia (Higgs & Gilleard, 2015; Holstein & Minkler, 2007; Van Dyk, 2014). I identified that homecare workers found it more challenging to involve and offer meaningful choices to people living with more

advanced dementia. Homecare workers had an understanding and appreciation of person-centred care in theory, yet in practice with clients living with advanced dementia, it was more difficult to achieve.

Relating this to Kitwood's work (1997a), as dementia progresses and cognitive functioning declines, homecare workers may have less opportunity to learn about the attributes of an individual's personhood, and thus caregiving regresses to focusing on the individual as a biological being, responding only to what Maslow depicted as low-level fundamental needs (1943) (see Chapter 1 section 1.2.3). Like other studies looking at care work in hospital and residential settings (Scerri et al., 2020), my work identified that homecare workers often prioritised clients fundamental physiological needs such as personal care and medication management, over the higher level emotional and relational needs, and opportunities for personal fulfilment. This occurred when homecare workers worked towards a time-and-task focused approach, as well as with clients who had more advanced dementia and diminished communicative ability. Providing care in clients' own homes, surrounded by their possessions and life memories, can enable homecare workers to learn about the individual and the attributes that define their personhood, regardless of the client's stage of dementia or communicative ability.

In the literature, family carers are often situated as proxy decision-makers for relatives living with dementia who have limited or diminished cognitive functioning (Carter et al., 2018; Livingston et al., 2010; Samsi & Manthorpe, 2013). My findings highlighted that homecare workers were sometimes positioned similarly, though with different moral and legal authorities. I highlighted the value of good relationships and collaborative working between homecare workers and family carers; homecare workers may be able to draw upon family carers in promoting meaningful choice and decision-making in people living with advanced dementia. This likens to Higgs and Gilleard's (2016) debate, that it is the responsibility of others to maintain personhood of, and person-centred care for, people living with dementia. Previous research has explored the processes adopted by family carers in meaningful decision-making with relatives living with advanced dementia, including utilising

knowledge of their relative's life story as an extension of their identity on which to base decisions (Elliott, Gessert, & Peden-McAlpine, 2009).

9.3.3 Feminism and the emotional labour of care

As discussed in Chapter 1, the homecare workforce in England is predominantly female (Skills for Care, 2019), which is closely reflected in the sample of homecare workers who participated in my ethnographic study. I therefore have drawn closely upon feminist-driven theories of the emotional labour of care, in considering gender-related risks for homecare workers who provide care to people living with dementia, focusing on potential exploitation and sexualisation of the role.

9.3.3.1 Gender-related risks: exploitation

In Chapter 1, I applied emotional labour theory in considering that perceived job satisfaction in doing something good for others may justify female care workers' tolerance of poor working conditions (i.e. low pay, limited or no supervision or training, and unstable working hours) (Folbre, 2012; Rubery & Urwin, 2011). Concerns regarding emotional exploitation of female-dominated workforces (Ward & McMurray, 2016), were echoed in my work with homecare workers. I demonstrated amongst homecare staff, a sense that providing care outside of contracted hours was associated with doing the job well, with many staying in their own unpaid time to ensure clients were sufficiently cared for. This has also been found with care home staff who perceived working in their own time as beneficial to the residents, yet at detriment to their own emotional vulnerability (Johnson, 2015).

In the BOUGH project, Turner and colleagues (2018) used the term 'going the extra mile' to depict voluntary labour. As in my findings, this included homecare workers giving their own time, money and goods to their clients and family carers. Their depiction of 'affective voluntary labour' perceived homecare workers' compassionate and empathic nature as intrinsic to their identity; the authors described this to be in accordance with their personal identities as daughters, granddaughters and friends (Turner et al., 2018). This characterisation of voluntary labour concerned care workers' motivations to build relationship with clients and the

impact of strong emotional attachments on care workers' own wellbeing, particularly when clients died (Turner et al., 2018).

Like Turner et al. (2018), I found that homecare workers often took on the role of friend or personal companion when caring for people living with dementia, likening their female clients to an aunt or grandmother, and in turn, they were described by family carers and clients as like a daughter or a friend; roles akin to traditional societal perceptions of women's role identity, with intrinsic gendered-characteristics to nurture, empathise and harmonise (Müller, 2019). The 'prisoner of love' framework (introduced in Chapter 1) amplifies that these inherent caring qualities make women naturally well-suited to caring professions, yet put women at greater risk of exploitation within health and social care industries (Folbre, 2012; Müller, 2019). Manthorpe, Harris, Samsi, and Moriarty (2017) discussed caring professions as drawing upon the innate caring abilities of women, as opposed to nurturing their caregiving skills through formal learning and training.

9.3.3.1.1 *Practical versus emotional labour of care*

Bolton and Wibberley (2014) posited that physical and emotional labour are separate components of care, divided by the nature of homecare in practice; the care plan considers the physical tasks, while emotional work is 'informal' or voluntary labour, often in response to expectations from key stakeholders, that homecare workers are required to navigate autonomously. My findings showed that role ambiguity was associated with challenges faced by homecare workers in negotiating tasks outlined in the client's care plan, and expectations of clients and family carers that reflected their preference for flexible, responsive, person-centred care. There is a disconnect therefore, between the explicit expectations guided by the care plan, and the implicit expectations, akin to emotional labour, that are not instructed and are therefore left to homecare workers to navigate, often without support. Whilst homecare workers' relational and emotional skills were those that were valued by people living with dementia and their family members, they are not harnessed nor rewarded by care models adopting a time-and-task focused approach.

9.3.3.2 Gender-related risks: sexualisation

While exploitation of female care workers has been more widely written about, sexualisation has been less so, but was apparent in my findings. Some observations revealed situations where male clients displayed inappropriate touching and referred to their homecare workers with romanticised or sexualised terms, such as 'baby'. These behaviours were often accepted or normalised by female homecare workers, who in turn, used reciprocal terms such as 'handsome' when referring to their male clients living with dementia.

Inappropriate sexual behaviour towards care staff is complex and difficult to manage (Mallon, Krska, & Gammie, 2019; Nielsen & Jørgensen, 2016; Ward & Manchip, 2013), yet the current evidence-base is sparse, particularly around care for people living with dementia. In a qualitative study by Nielsen and colleagues (2017), sexual harassment of care staff most often occurred with clients with cognitive impairments, including dementia, during personal care. Inappropriate behaviours from clients with cognitive impairments were not perceived by homecare staff as intentionally harassing; care workers avoided using the term 'harassment' to describe sexualised behaviours of their clients (Nielsen et al., 2017). Care workers often were unsure of how to respond or manage such situations. Some described normalising such behaviours as a part of their everyday work (Nielsen et al., 2017); perhaps because the perceived alternative was to blame the client. In my findings, I presented a situation where a homecare worker responded to a client's inappropriate behaviour using humour and seemed to perceive the behaviour as a normal part of their relationship. Normalising and using humour were seen by this homecare worker as effective strategies for completing necessary care tasks.

9.4   Implications for dementia-specific training for the homecare workforce

In this section, I discuss the implications of my findings for developing dementia-specific training for the homecare workforce, and where providing this is likely to require organisational practice-level change. I discuss how my work influenced the development of the NIDUS-Professional intervention (Chapter 8).

Many campaigns and organisations have highlighted the potential role of a better trained and supported homecare workforce in improving support for people with dementia to live well at home, with good quality, meaningful care that promotes independence and choice (Carter, 2016b; Department of Health, 2015c; Hussein & Manthorpe, 2012; NHS England, 2016; NICE, 2013a; Prince et al., 2014; Public Health England, 2018). My findings contribute to a growing body of evidence about how this might be achieved (Polacsek et al., 2020; Schneider et al., 2019). I discuss below three factors I have identified as key considerations for training and supporting the homecare workforce to include: 1) relationship-focused and person-centred care; 2) working in clients' homes; 3) recognising the value of the homecare role. These mirror, to some extent, the work of Parveen et al. (2021), which suggested that existing training programmes fail to address organisational support, and promotion of staff autonomy and wellbeing.

9.4.1   Relationship-focused and person-centred care

The UK Home Care Association (UKHCA) called for homecare to facilitate relationships between people living with dementia and their care workers, which promote and protect the dignity and independence of the individual (Carter, 2016a). To do this, homecare workers must be equipped with the necessary skills to provide relationship-focused, person-centred care that was evidently valued by people living with dementia and their family carers. Implementing person-centred care plans at an organisational level may address the constraints of task-orientated care.

In applying my findings to the development of the NIDUS-Professional intervention, value was placed on homecare workers using empathy, listening to clients and understanding how their behaviour may also be communication, to develop positive relationships with clients living with dementia and their family carers, within a supportive, professional and flexible framework. Homecare providers prioritising continuity of care, with small consistent teams of homecare workers for each client, helps facilitate positive client relationships. Current NICE guidance prioritises continuity of care as key to the delivery of person-centred care at home for older people (NICE, 2016b).

9.4.2 Working in clients' homes

I posit that care that is person-centred need also be home-centred, respecting the client's home as an extension of self. I highlighted the home as a place of familiarity for people living with dementia, and the risk that the presence of homecare and homecare workers can be depersonalising. Training can convey the importance of extending respect and dignity not only to clients, but also their homes. In supporting independence, it is necessary to find a balance where clients can live at home in the way that they want, within the protective boundaries that keep them safe and facilitate dignified, quality homecare. Therefore, where changes or adaptations to the home are necessary, it is important to protect its familiarity; as stated by Cahill (2018), changes to facilitate homecare should not reduce autonomy, independence, dignity, nor heighten changes to the self for people living with dementia.

Homecare workers often work in isolation and without an anchoring workplace. Having space within agency offices for homecare workers to store personal belongings may help to reduce the 'presence' of homecare within the home. Visiting the office more frequently may increase the support, both formal and informal, that homecare workers receive from managers and peers.

9.4.3 Recognising the value of the homecare role

Recognising the value of homecare workers' role and supporting their emotional needs, are key to delivering the Prime Minister's vision to make homecare a more 'attractive' profession, as stated in the Challenge on Dementia 2020 (Department of Health, 2015c). The NIDUS-Professional intervention encourages homecare workers to recognise the value in their work, and through promoting peer, and managerial support, seeks to address the perceived powerlessness that was at times reflected in my ethnographic work. Facilitating opportunities for peer support, team-based working and reflective practice may support homecare workers' emotional needs and increase recognition of the value in their work, particularly around the meaningfulness of relationships with clients.

My findings support the UKHCA's call for training that provides 'greater flexibility for homecare providers to innovate and shape care with the individual' (UKHCA, 2015). I highlighted the potential value of homecare workers' knowledge of their clients within the client's multidisciplinary care team. Training can equip homecare workers with skills to communicate and work with health and social care professionals, yet this is likely to require change at a practice level, as I discuss below.

Moreover, increasing and strengthening the workforce was envisioned to enable more people with dementia to remain living at home by providing homecare suitable to the needs of the individual and their families (Department of Health, 2015c). My findings highlighted the importance for training to clearly acknowledge the value, and also the complexities and constraints of the homecare role, as unrealistic expectations can have a detrimental impact on care provision and homecare worker wellbeing. Homecare agencies may wish to further address this by developing a clear message from the start of the service, outlining the scope of the role to set and manage expectations for clients living with dementia and family carers. Valuing the homecare role is about defining what it can be, but also what is beyond reasonable expectations of a valued professional.

In Figure 9.2, I summarise the key skills that I have highlighted as important in providing homecare to people living with dementia and supporting their independence. While these are not all dementia-specific, they require particular consideration with clients living with dementia, in whom loss of memory can increase reliance on the home as a repository of personhood, and on homecare workers' skills to build and maintain positive client relationships. As mentioned above, organisational practice-level changes are necessary to fully implement into practice, what homecare workers learn from training.
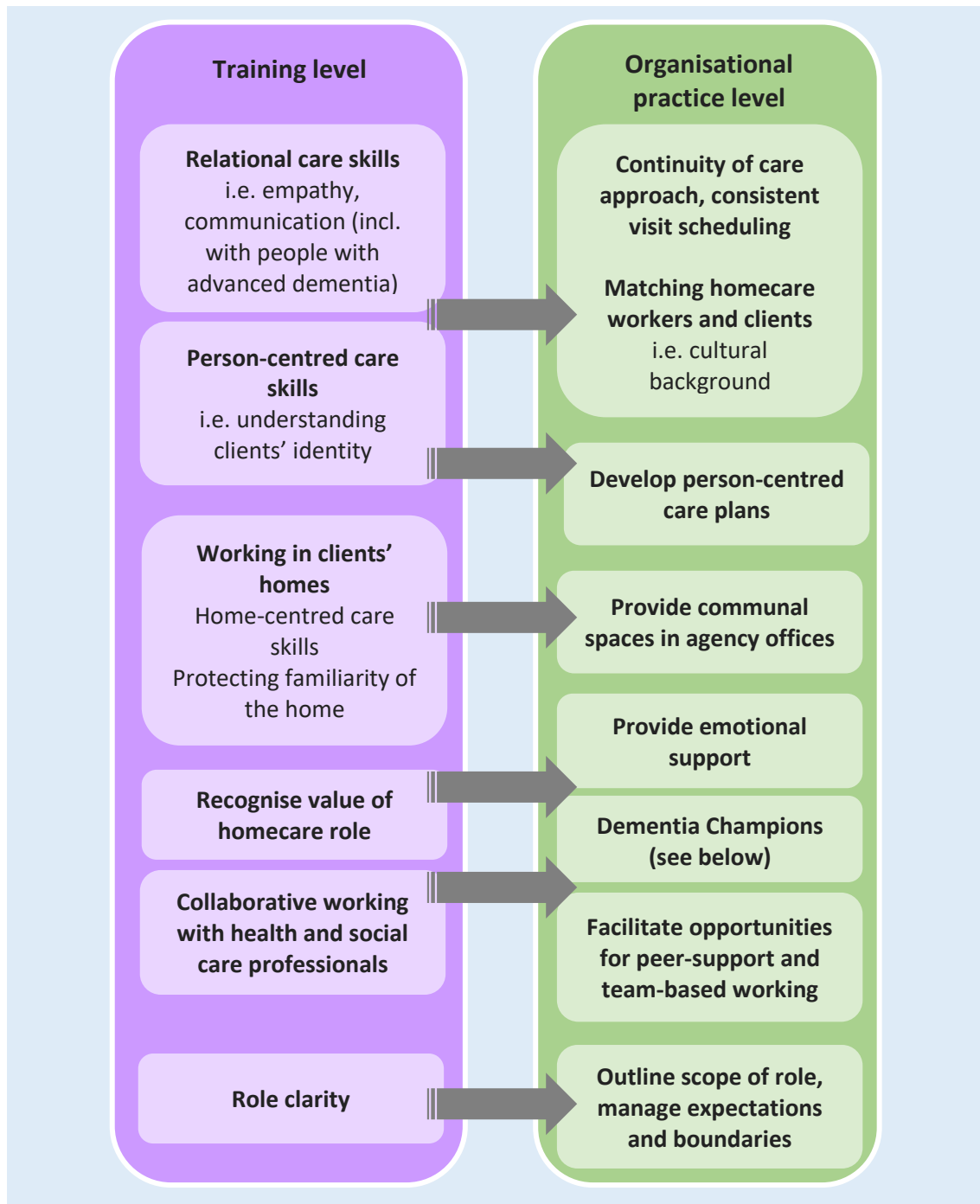
Figure 9.2: Key considerations at a training and organisational practice level

9.4.4 Learning from dementia-specific training in care homes

The homecare sector can learn from evidence for effective dementia-specific training in care homes. The Improving Wellbeing and Health for People with Dementia (WHELD) programme has increased quality of life, health and wellbeing of people living with dementia in care homes (Ballard et al., 2020; Whitaker et al., 2014). The

programme trained care home staff in person-centred care. This training had five components: understanding dementia and person-centred care, understanding the relationship between an individual's experience and their behaviour, enabling staff to recognise the impact of staff and residents' interactions, embedding self-assessment practices into care homes relating to person-centred care delivery, and implementing person-centred care principles into planning and individualised care practices (Whitaker et al., 2014).

Mirroring my own findings, 'recognising the value' was one of three key themes developed in a qualitative study interviewing care staff participating in the WHELD programme (Fossey et al., 2019). Where staff perceived the WHELD approach to have benefits for their work, its elements were better sustained. Staff found it helpful to reflect on their care practices as a team (Fossey et al., 2019). This reflects my recommendations for homecare training and support to be team-based, with opportunities for shared learning and development.

9.5 Implications for policy around homecare from a rights-based approach

In this section, I will firstly consider policy implications of my work pertaining to good quality care for people living with dementia, followed by implications for provision of better support for the homecare workforce. I will explore both these areas from a rights-based approach.

9.5.1 Quality homecare for people living with dementia

Global policy strategies emphasise a drive towards improving quality of life and quality of care for people living with dementia, through supporting independence, autonomy, self-determination, participation and choice in their daily lives (Cahill, 2020). This rights-based approach is highly relevant to homecare provision for people living with dementia. My ethnographic work focused on promoting independence as a key dimension of what constitutes good quality care for people living with dementia (Polacsek et al., 2020; Pollock et al., 2020; Turner et al., 2018). Looking at how this can be achieved through better training and support of the homecare workforce is

one fundamental dimension of ensuring quality homecare for people living with dementia; implementing policy change to reflect this in practice is another.

Quality homecare has the potential to enable people living with dementia to remain at home for longer, possibly reducing the longer-term economic impact of dementia on public finances, although passing some of these costs to family carers. In 2015, the social care cost in England, in terms of public funding of people living with dementia in the community (£1.0 billion), was considerably less than public expenditure on those living in care homes (£7.1 billion) (Wittenberg et al., 2019). Greater investment in social care in the community may save money in the longer term by delaying people moving into more costly residential care.

The Global Action Plan on Dementia (World Health Organisation, 2017b) provides a contemporary outline for agenda change, for countries committed to better quality of life and care for people living with dementia. The Plan places an emphasis on personalised, person-centred and empowering care for people living with dementia, moving away from policies that are restrictive and instead recognising the need for sustainable funding, training and empowerment of those affected by dementia to operationalise the Plan (Cahill, 2020). These are concepts that were highlighted throughout my ethnographic work, for example, identifying that homecare workers have the potential to empower their clients living with dementia, which could be achieved via a collaborative, interdependent, relationship-focused care approach that understands and values the identity and personhood of the client as an individual beyond their dementia diagnosis.

Below, I will consider the applications of these key concepts in relation to my findings regarding the provision of homecare for people living with dementia: firstly, the more general concept of personalised care, and secondly the concept of person-centred care, specifically challenges to the delivery of person-centred care; a dementia-focused concept, theoretically driven by Kitwood (1997b).

9.5.1.1   Personalised care

The NHS Long Term Plan in England seeks to enable people to age well, including supporting people to live more independently at home for longer (NHS England,

2019). My ethnographic work highlighted the importance of considering client identity in care, in other words, of personalised care. Personalised care will enable care recipients to have more control and choice in how their care is planned and delivered, based on what is identified as important to each individual. Pertaining to the innovative models of care identified by The King's Fund (outlined in Chapter 1), a personalisation model was the only approach found to be implementable at scale (Bennett et al., 2018), and can be considered better suited to respond to individual wants and needs of people living with dementia, by promoting choice in how homecare is both commissioned and delivered (NHS England, 2021b).

In practice, personalised care can be reflected in clients' care plans. Having a continuity of care approach has the potential to enable consistent homecare workers to collaboratively and iteratively be involved in developing and reviewing clients' care plans, in an on-going process of collaboration with those involved in their care. Dementia is a progressive disease and individual needs will change over time, perhaps more quickly than clients without dementia. The Alzheimer's Society's Fix Dementia Care campaign (Carter, 2016b) recognised that homecare workers are well placed to identify changes in an individual's condition and behaviour, to reduce the impact of symptoms and to 'boost' family carers to keep going (Carter, 2016a, p. 10). This is also the premise of an autonomous team working model of care (outlined in Chapter 1), that has been associated with improved job satisfaction for care workers and person-centred care provision for clients (Bennett et al., 2018).

The small but not insignificant number of directly-employed care workers (also termed Personal Assistants) in England reflects a desire among some clients and families to have more input and control over their care (Woolham et al., 2019). Likewise, these workers value the variety of their work and opportunities to adjust to the client's needs and their relationships, although their working terms and conditions may be poor. A personalised care approach (i.e. that is reflected in clients' care plans), requires collaborative and integrated working amongst the care recipient and their health, social and public care services (NHS England, 2021b). This closely aligns with the Alzheimer's Society's call for the Government to end the divide

between health and social care, which they argue unfairly disadvantages people living with dementia (Prince et al., 2014).

9.5.1.2 Challenges to delivery of person-centred care

As discussed in Chapter 1 (see section 1.2.3.1), person-centred care is a concept often reported as the gold-standard for good quality care provision for people living with dementia (Gilster, Boltz, & Dalessandro, 2018; NICE, 2011). While the importance of providing person-centred care was frequently referenced in the narratives of homecare workers in interviews, observations revealed that this was more difficult to achieve in practice, exacerbated by organisational challenges including rigid, task-orientated care plans, time constraints, and when providing care to people living with advanced dementia. Providing homecare staff with person-centred dementia training has previously shown to improve attitudes towards people living with dementia, particularly concerning clients' decision-making abilities (Kingston, 2008).

9.5.1.2.1 Task-orientated care

While the care plan can be reflective of personalised care, previous research suggested that delivering care that was governed by the client's care plan was perceived as incongruent with a person-centred care approach (Polacsek et al., 2020). In my findings, one person living with dementia felt that the care plan redirected the homecare workers' attention away from the individual and their needs. Although planning and comprehensive documentation of care needs are necessary (Care Quality Commission, 2013), flexibility for care workers to be responsive in attending to the changing needs of clients outside of the rigid structure of the care plan is perhaps more important (Care Quality Commission, 2013; Sykes & Groom, 2011). Therefore, it is important to move away from care planning that is governed by a time-and-task approach, and instead develop care plans in a way that enables a more flexible way of working and encourages homecare workers to respond to the individual needs of the client at each visit; this will likely require longer, more expensive visits to move away from task-orientated care provision, towards a person-centred and relationship-focused care approach.

9.5.1.2.2   Time constraints

Commissioning longer visits for people living with dementia is likely to enable quality, person-centred and relationship-focused care. NICE guidance states that homecare visits for older people should be a minimum of 30-minutes, to meet individual needs and uphold the care recipients' safety, dignity and wellbeing (NICE, 2016b). Yet the guidance includes a caveat within this recommendation for minimum visit duration: 'except when short visits for specific tasks or checks have been agreed as part of a wider package of support' (NICE, 2016b, p. 19). This is perhaps where the guidance is failing to prevent the short 15 to 30-minute visits that were seen in my ethnographic study, where short visits to support personal care or meal preparation were perhaps considered acceptable. I identified that people living with dementia needed more time to be meaningfully involved in decision-making and daily tasks. Based on this, NICE guidance could promote 30-minute visits as the minimum length of time, regardless of tasks, when supporting clients living with dementia.

However, constraints in this sector are not uniform. People living with dementia in receipt of Local Authority funded care were those who we observed receiving visits of less than 30-minutes. In these short visits, homecare workers were focused on working quickly to complete tasks outlined by the care, yet the relationship-focused aspects of care, including companionship, were unachievable. I observed rushed care, as well as times when it was clear that people living with dementia needed more time if they were to be included in meaningful decision-making and tasks as active participants. Typically, privately-funded clients receive longer care visits (Atkinson, Crozier, & Lucas, 2018) which may facilitate the development of important homecare relationships.

9.5.2   Supporting the homecare workforce

My findings add to a growing body of literature recognising the value of homecare, and the need for homecare workers to be properly trained and supported to provide good quality care to clients living with dementia, with good working conditions. A rights-based approach is likely to require a whole systems collaboration to be achieved in practice (McPherson, 2020; McPherson & Abell, 2020).

9.5.2.1 Positioning within multidisciplinary care

THE UKHCA stated that for homecare to be appropriately recognised and valued, it is necessary for homecare workers to be identified as an integral part of the 'wider picture', playing a key role in a multidisciplinary dementia care approach (UKHCA, 2015, p. 8). I found that homecare workers had little opportunity to contribute to clients' multidisciplinary healthcare. This is also dissonant with NICE guidelines, which support joint working between healthcare professionals and homecare workers to ensure integrated and person-centred care (NICE, 2015a). Coordination of services supporting the health and social care needs of people living with dementia is required to respond to clients' needs and support continuity of care (Polacsek et al., 2020). These policy changes could be targeted at a community service level, to facilitate the coordination between clients' multidisciplinary care services, including homecare.

9.5.2.1.1 The role of 'Dementia Champions'

Coordinated care across services could be achieved by developing the role of 'Dementia Champions' in homecare agencies, where senior homecare workers are positioned as the link between clients, the homecare provider and health and social care services. Some homecare providers report having appointed Dementia Champions in their teams, yet the role is predominantly to improve understanding and raise awareness of dementia, much like the Alzheimer's Society's 'Dementia Friends' initiative (Alzheimer's Society, 2017a) outlined in Chapter 1, as opposed to playing a role in care planning and coordination. The concept of a Dementia *Friend* depicts a voluntary role, while a Dementia Champion is perhaps more fitting with a professionalisation agenda.

The Dementia Champion role has been utilised across services to recognise and develop staff members who are more specialised in working with people living with dementia. The WHELD programme positioned care home staff selected by their managers to be Dementia Champions, who cascaded knowledge from additional training and support they received to other colleagues (Fossey et al., 2019). This reportedly changed the balance of leadership, facilitated team working, and empowered staff to develop in their roles. Many NHS Trusts have also adopted the Dementia Champion role. The nature of the role differs across Trusts, but typically

involves staff having a key role in contributing to planning and developing care provision for people living with dementia, across social care and NHS health settings, and promoting multidisciplinary working (Banks et al., 2014; NHS England, 2021a). Establishing Dementia Champions more widely across health and social care services, including homecare, could facilitate collaborative working; Champions across services could act as points of direct contact amongst one another, to streamline the process of a coordinated dementia care approach.

For the homecare workforce, this could be implemented within existing training programmes, for example, drawing on the Dementia Training Standards Framework developed by Health Education England (Skills for Health et al., 2015) that I outlined in Chapter 1. Training to become a Dementia Champion could be situated in tier 3 of the framework, for key staff or 'experts' working in leadership roles with people living with dementia. This would require protected time, additional support and status to do this.

9.5.2.2 The role of agency managers in supporting homecare workers

The research presented in this thesis builds upon the BOUGH study's organisational implications for homecare policy and practice, giving attention to the role of homecare managers (Pollock et al., 2020; Schneider et al., 2019; Turner et al., 2018). The authors considered the importance of recruitment, encouraging homecare agencies to employ staff whose caring approach aligns with a 'moral hierarchy' that prioritised valuing care recipients as individuals, irrespective of their mental capacity. In return, agency managers must ensure homecare workers feel recognised and valued for the work that they do.

My findings highlighted the importance of open communication, such as managers adopting an 'open door' approach, providing an anchored workplace for homecare workers, as well as the use of communal spaces within agency offices for homecare workers to informally visit; Manthorpe et al. (2019) similarly found that having a space to 'drop by' the agency's office unannounced helped to reduce feelings of isolation in homecare staff. Care staff's perceptions of being supported and valued

relate to good communication and positive interpersonal relationships with homecare managers (Ryan et al., 2004).

I found that peer support and a sense of belonging to a team were important for homecare workers; although my findings, amongst others, highlighted limited opportunities in homecare training or practice to interact with peers (Manthorpe et al., 2019; Ravalier, Morton, Russell, & Rei Fidalgo, 2019; Yeh et al., 2018). Having Dementia Champions within homecare agencies would further facilitate both team working and team learning, as staff who are more specialised in dementia care could work with other homecare workers to develop and practice their dementia-specific knowledge and skills.

9.5.2.3 Homecare workers' rights

People living with dementia often have complex care needs which are not reflected in the support, pay, value or general working conditions of homecare workers. As identified by Parveen et al. (2021), important factors exist beyond the learning content that current dementia-specific training provides, including organisational practices and support of staff wellbeing and rights. I identified, for example, homecare workers' support needs around grief and anticipated grief. Training can help to prepare homecare workers for the loss of clients and dealing with the difficult emotions that were sometimes associated with the role. Beyond training, homecare agencies can support staff by making practical arrangements, for example, by enabling staff to attend clients' funerals (Yeh et al., 2018). This is pertinent in light of the COVID-19 pandemic which I will discuss in more depth below [see section 9.7.3.1].

In Chapter 1, I highlighted research by Kadri et al. (2018) that explored personhood of care home staff in providing person-centred care to people living with dementia. Finding that care home staff felt undervalued by their employers who perceived them as an instrument in which to provide person-centred care, the authors commented that enhancing and valuing personhood of care staff, meeting their needs for support and respite from emotional burden, should be an explicit dimension of quality standards and supported both in policy and practice (Kadri et al., 2018). My work

builds upon this and relates closely to relationship-focused care theory, highlighting that without sufficient support and recognition to legitimise the value of their work, homecare workers felt disempowered and the value of their work and relationships with clients went unnoticed.

My findings highlighted organisational practices such as consistent scheduling to facilitate the valued relationships that developed between homecare workers and their clients living with dementia. However, significant barriers exist that challenge this continuity of care approach that requires sufficient funding, staffing stability and capacity. Care workers on zero-hour contracts experience employment instability and poor mental health (Ravalier et al., 2019; Skills for Care, 2018); training and support cannot compensate for financial instability. Few homecare agencies receive funding to provide specialist dementia support (Challis et al., 2010) and whilst care commissioning arrangements focus on reducing costs as a consequence of austerity and a diminished social care budget, homecare workers will continue to be under-supported (Davies et al., 2020).

9.5.2.4 Strategies for change through unionised support

A recent report by Skills for Care outlined the role of unions, regulators and commissioners, in attaining better support, pay and working conditions for the social care workforce (Skills for Care, 2021).

An Ethical Care Charter was developed by UNISON, one of the largest trade unions in the UK, in response to issues raised about the homecare sector (UNISON, 2017). My findings echo many of the issues raised by homecare workers in a UNISON survey (2013). These included 'call cramming', leading to homecare workers rushing visits, or staying in their own unpaid time out of a sense of loyalty or duty. Problems with discontinuity of care negatively impacted relationships with clients (especially clients living with dementia), and the impact of isolated working on homecare workers' morale and role development.

The Ethical Care Charter aims to establish a baseline for ensuring quality, dignified and safe care by improving employment conditions for care workers and establishing a more stable workforce (UNISON, 2017). In addition to increasing homecare

workers' pay to the Living Wage, pivotal strategies outlined by the Charter for the commissioning of homecare services included: abolishing zero-hour contracts and 15-minute visits for clients, paying homecare workers for travel time and sick leave, providing them with regular training 'to the necessary standard to provide a good service (at no cost to themselves and in work time)', and to facilitate regular opportunities to meet with co-workers (UNISON, 2017, p. 9). Prioritising care providers that have signed up to an Ethical Care Charter is suggested as a way for care commissioners to distinguish ethical and transparent employers and care providers (Atkinson, Sarwar, & Crozier, 2019; Hudson, 2019). While 39 English Councils have adopted the Charter (UNISON, 2021), the majority have yet to do so.

9.5.2.5 Professionalisation of the homecare workforce

There is a known workforce crisis in England's social care system; without trade union membership, homecare workers have limited support and poor working conditions (Dromey & Hochlaf, 2018). For example, my ethnographic work has shown that as the main place of work for homecare workers, clients' homes that are poorly suited for care provision to people living with dementia pose health and safety risks for both the clients and their care workers; domestic support, however, is not covered under the Health and Safety at Work Act 1974 (HSE, 2020). Without this support, or that of a union, homecare workers have limited support or protection at work.

The UK Home Care Association's (UKHCA, 2015) call for more consistent training for the homecare workforce includes advanced accredited training qualifications to allow specialisation, such as dementia care. There is a strong argument in favour of professionalising the social care workforce to tackle the endemic problems inherent in adult social care (Dromey & Hochlaf, 2018); however professionalisation is a heavily debated topic. Regulated working policies have the potential to improve quality of care for clients, as well as recognition, perceived value and working conditions for staff (Scales et al., 2017). Achieving qualifications and competencies that validate knowledge acquisition may bring status, monetary rewards and improved working conditions (Giordano, 2020), and reduce staff turnover (Davies et al., 2020; Skills for Care, 2018).

The Care Certificate (Skills for Care, 2015), described in Chapter 1, is not currently a mandatory requirement for care staff, yet making it so, enforced by the CQC and maintained by Skills for Care, is one suggestion for transitioning into a professionalised sector, using an already established tool (Dromey & Hochlaf, 2018; Kingsmill, 2014). Professionalisation of the sector would provide the workforce with the value and reward that is necessary to make care work an 'attractive profession' (Department of Health, 2015c, p. 31). However, it is feared that the pressure on care workers to register and attain qualifications will drive staff away from an already short-staffed workforce (Hayes, Johnson, & Tarrant, 2019).

9.5.2.5.1 Learning from cross-cultural approaches to professionalisation

Below, I consider what the English care system may learn from two countries that could be considered as pioneers: Sweden, where the homecare workforce has been largely professionalised, and Japan, where there is the world's most aged population and high prevalence of dementia (Cabinet Office Government of Japan, 2016) has pioneered advancements in the way dementia care is provided.

<u>Sweden</u>

Scandinavian models of care have undergone an organisational shift towards professionalising the social care sector. Professionalisation was intended to improve both service quality and gender equality in social care, by increasing the competency of 'non-educated' care staff (Moberg, Blomqvist, & Winbald, 2017). In Sweden, care workers providing support to older adults are either degree-educated nurses (7%), nursing assistants with upper secondary education or vocational training (53%), or care assistants without formal competency training (32%) (SALAR as cited in Moberg et al., 2017; Vingare, Giertz, & Melin Emilsson, 2020). Other care workers include people with additional health or care training, i.e. physiotherapists (8%) (SALAR as cited in Moberg et al., 2017). Motivations for continuous improvements to the sector are achieved via performance-based targets set by the central Government, on outcomes for older adult care recipients (The King's Fund, 2014).

Learning from this model may increase motivation to attain qualifications for those who wish to within the workforce, enabling staff to specialise in working with clients

with complex care needs, including people living with dementia. However, becoming more specialised through advanced training and qualifications may bring forth other challenges. One study looked at perceived job strain amongst dementia homecare specialists in one Swedish homecare service (Sandberg, Borell, Edvardsson, Rosenberg, & Boström, 2018). Dementia specialists reported higher levels of job strain than other homecare staff, relating to wanting to do more for their clients than was permitted by their employing organisation, and feeling their opinions regarding clients' care were undervalued (Sandberg et al., 2018). This suggests that professionalisation alone cannot surpass the intrinsic challenges and constraints embedded within organisational care practices, including staff support.

Moreover, there are key differences between England and Scandinavian countries such as Sweden that make it difficult to draw comparisons regarding the state of social care. Unlike in England, 80% of social care provision for older adults in Sweden is publicly provided as part of the universal Swedish welfare state, meaning everyone is entitled to publicly-funded care regardless of an individual's personal circumstances (Moberg et al., 2017). However, England's population is almost six times larger than that of Sweden's, and public spending on social care in Sweden is amongst the highest out of 27 countries included in the report by the Organisation for Economic Cooperation and Development (OECD) (The King's Fund, 2014), making it difficult to draw comparisons.

Japan

I was able to learn about the aged care system and community care for people living with dementia in Japan, when I visited the Tokyo Metropolitan Institute of Medical Science in 2019. With one in four people living in Japan aged over 65 years, and the rising prevalence of dementia, Japan has the largest older population in the world and parts of its aged care system are considered by some to be world-leading (Annear et al., 2018). There are currently 4.6 million people living with dementia in Japan (Ninomiya, 2015). To enable people living with dementia to remain at home for as long as possible, high value is placed on professional dementia education amongst both aged care workers and volunteer supporters, as outlined in Japan's The New

Orange Plan for integrated community care systems (Japan Health Policy Now, 2020; Nakanishi & Nakashima, 2014).

Community dementia care is provided by an integrated system of care workers and professionals, including home helpers, certified care workers and nurses, typically managed and coordinated by certified care managers (Murashima, Nagata, Magilvy, Fukui, & Kayama, 2002). Nationally, home helpers are required to undertake 500-hours of basic vocational training, while those wishing to develop further in the role can complete additional training consisting of 50-hours to obtain a 'third-class license', 130-hours for a 'second-class license', and 230-hours for a 'first-class license'; a first-class license is the most specialised, pertaining to senior home-helpers (Japan Academy of Gerontological Nursing, 2012). Care workers can become certified by passing an examination following graduation from a Ministry of Health, Labour and Welfare designated training school, or after working in a personal-care related occupation for three years or longer (Japan Academy of Gerontological Nursing, 2012). The care manager certification is obtained via an optional examination for those wishing to attain a long-term care leadership role. The accessibility of the certified care exam for all care workers created an insecurity amongst nurses in Japan, around distinguishing their role from that of a certified care worker. Professionalisation of the care worker role in community-based dementia care therefore raised the status of the role to the extent that it infringed on the nursing role within multidisciplinary dementia care.

Moreover, the Japan National Campaign of Dementia Supporter Caravan was launched in 2005 to create a community support system by educating volunteers from the public. Volunteers complete a training programme that aims to raise awareness of dementia and provides education on how to support people living with dementia in the community (OECD, 2015). Over 10-million people in Japan have completed the 'Dementia Supporter' training (Aihara & Maeda, 2020). While the programme was found to have improved attitudes towards people living with dementia (Kim & Kuroda, 2011, as cited in Aihara & Maeda, 2020), a more recent study highlighted limited real-world impact, suggesting that a lack of action had been

taken by the volunteers to support people in the community, six-months after completing the training (Aihara & Maeda, 2020).

Like Sweden, Japan has a long-term care insurance system, introduced in 2000, which equally supports both health and social care needs of people living with dementia, including homecare (Centre for Policy on Ageing, 2016). While funding and access to community care are crucial differences in terms of accessibility of social support for people living with dementia in England, the English Government sought to learn from Japan's cost-effective strategies to social care, such as increasing public education to develop a scheme of dementia supporters and volunteers (Department of Health and Social Care, 2012b; Hayashi, 2013). This developed into the 'Dementia Friends' initiative that I have previously discussed (Alzheimer's Society, 2017b). However, drawing on voluntary labour cannot equate to the level of need that people living with dementia have, which can be achieved by providing better training and support to the already established social care workforce. This may further warrant the establishment of Dementia Champions within homecare services as I have suggested above.

9.6   Strengths and limitations

In the next section, I will outline the strengths and limitations of the work presented in this thesis.

9.6.1   Originality and representativeness

The research presented in this thesis is one of few studies to use ethnographic methods to explore homecare for people living with dementia. There is also limited research exploring training for homecare workers that includes the perspectives of people living with dementia. A major strength of this thesis was the inclusion of different participant perspectives to explore my research objectives. Through participant observations, I was able to capture the lived experiences of people living with dementia who may have been unable to take part in other forms of research, from the lens of the observers. This supports the notion that ethnographic methods

in research are well suited to include people living with dementia, particularly those with more severe or advanced dementia (MacLaren et al., 2017).

9.6.1.1 Sampling and recruitment

The strengths of collecting data as part of a team enabled me to reach a wider and more geographically diverse sample of participants and homecare agencies. However, whilst diverse in location, the six homecare agencies involved in the participant observations are unlikely to be representative of all homecare providers in England. Whilst I sought to recruit homecare agencies with varying CQC ratings, the final sample included five agencies rated 'Good' and one rated 'Outstanding'. One agency underwent an inspection just before my field visits began and their rating changed from 'Good' to 'Requires Improvement'. While the six agencies may not be representative of homecare providers with poorer CQC ratings, the majority (80%) of registered social care services in England have a 'Good' CQC rating (Care Quality Commission, 2020).

We recruited homecare workers through homecare managers, who may have selected the 'best' homecare workers only to take part in the observations, to represent the agency in a positive light. Ongoing communication with agencies and building rapport with managers may have minimised this bias, as we were able to emphasise the rationale for the research and that we were not making judgements on quality of care provision.

I attempted to recruit diverse participant samples. The interviews included an even balance of male and female participants of people living with dementia and family carers, but (unsurprisingly as it is a female-dominated sector) more female homecare staff and health and social care professionals. The participant observation sample included more female than male clients living with dementia and only female homecare workers were observed. Whilst there was some diversity in ethnicity, most participants were White British. My findings therefore may not be entirely representative of all stakeholders in homecare. However, the characteristics of participants included are not dissimilar to the general statistics of people in England who work in homecare and of people living with dementia who receive homecare;

85% of homecare workers in the UK are female (UKHCA, 2016) and there is a higher prevalence of dementia among women (Prince et al., 2014).

9.6.1.2 Data collection strategies

Data collection was often limited by practical situations of the researcher-observers. We observed only homecare visits during the day, although homecare visits for people living with dementia can take place in the evening and occasionally overnight. Overnight visits may have presented a side of homecare that was not captured, such as additional challenges for homecare workers in hours where there is less agency support (Swedberg et al., 2013). Night-time walking or wandering is sometimes undertaken by people living with dementia and has been frequently reported by family carers as contributing to high levels of stress and caregiver burden (Livingston et al., 2017). Likewise, staff working in care homes have reported burden at night, without support from management despite a frequency of 'incidents' with residents living with dementia overnight (Nunez et al., 2018).

I included supportive quotes and fieldnotes from all six homecare agencies, and from most of the homecare workers and clients observed, to represent all locations and experiences. I spent the most time in one agency, observing a greater number of homecare workers and clients living with dementia than we did in any of the other agencies. I therefore sought to reflect on some of the differences between agencies, particularly this agency in comparison to the others. The presence of a researcher during homecare visits may have had the potential for the Hawthorne effect (Sedgwick & Greenwood, 2015) on those observed. We attempted to minimise this possibility on participants via the familiarisation visits, which were aimed at facilitating familiarity and to prevent any change in participants' behaviour as a result of the presence of the researcher-observer.

Moreover, there is some debate that rapid ethnographic approaches are a superficial methodology (Knoblauch, 2005) with the potential to jeopardise the richness of data (Pink & Morgan, 2013). However, rapid approaches are becoming more common in health and social care settings where they are considered well-suited to the more immediate priorities and concerns of such sectors (Burgess-Allen & Owen-Smith,

2010; Vindrola-Padros & Vindrola-Padros, 2018). Knoblauch (2005) argued that short duration in the field can be compensated for by intensive data collection and analysis, with a focus on large amounts of data collected over a short period of time, which I believe my work achieved. Despite collecting data as a team and being able to conduct more observations than if I had been a lone-researcher, I found that I did not have enough time to include all interested persons living with dementia, within the agencies I observed; there were two additional clients for whom the homecare workers and I were unable to co-ordinate our schedules. Conducting observations can be physically and emotionally demanding on researchers (Wray, Markovic, & Manderson, 2007); leaving more space and time to reflect on homecare visits was perhaps a more effective approach than 'visit-cramming', in enabling the research team to produce rich and meaningful data.

9.6.2 Triangulation and credibility

Qualitative ethnographic methods have been critiqued for their intrinsic subjectivity. Whilst I took measures to advance the quality of my research, namely data triangulation, clear detailing of the methodology, reflexivity and 'fair dealing' (Mays & Pope, 2000), qualitative research should be judged for its credibility and confirmability, rather than conventional criteria for quantitative research such as validity and reliability (Merriam, 1985).

Participant observations (including visual sketches and photographs) and qualitative interviews are complementary ethnographic methods that enabled me to triangulate my data, producing rich and comprehensive findings (Mays & Pope, 2000). Using the 'Following a thread' approach (Moran-Ellis et al., 2006) to analyse the data, I found that the observation data provided a more in-depth account in adjunct to many of the topics participants discussed in interviews, as well as context to situate interactions and challenges described in interviews.

Establishing consistency in data collection amongst the researcher-observers proved challenging initially, with each researcher positioning themselves in the field and approaching fieldnotes in slightly different ways. Regular meetings sharing fieldnotes and engaging in reflective practice helped to harmonise the team. Furthermore,

involving the wider NIDUS team in analytic discussions aided collective sensemaking (Vindrola-Padros, 2021b) and mediated the possibility of the data being misinterpreted or overshadowed by my perspective alone, as the lead researcher.

I did not attempt to seek permission to take photographs of people, or from within clients' homes; doing so could have added a greater level of depth and richness to my findings. It is thought that ethical review boards may be overly restrictive in their consideration of visual research methods as confidentiality and participants' anonymity cannot be upheld (Prosser & Loxley, 2008). Moreover, as I began sketching during field visits as a time-saving approach to written fieldnotes, there was no opportunity for training in producing visual notes and as such, the other researcher-observers did not feel comfortable to do the same. Therefore, the sketches incorporated into data analysis came from only two of the six homecare agency visits. This expands on the debate around the intimacy of sharing fieldnotes (e.g. Bikker et al., 2017), whereby the researcher-observers found ease in sharing written fieldnotes, yet sketching or producing visual images went beyond their realm of comfort. This may be because as academics, we are used to others reading our work, but perhaps the unfamiliarity of sketching felt more intimate and private.

9.6.2.1 Accessibility

Creating visual sketches of interactions and taking photographs of agency office environments, enabled greater accessibility of the 'field experience' to multiple viewers, beyond written fieldnotes (Knoblauch, 2005). This is likely to have aided collaborative interpretations of the data amongst the research team. I used the visual data when disseminating my findings. This was received particularly well when presenting my research to audiences outside academia, including with people living with dementia.

9.7 Implications and future directions

In this section I outline my key recommendations for homecare research, policy and practice pertaining to the work presented in this thesis. I summarise these in Figure 9.3.
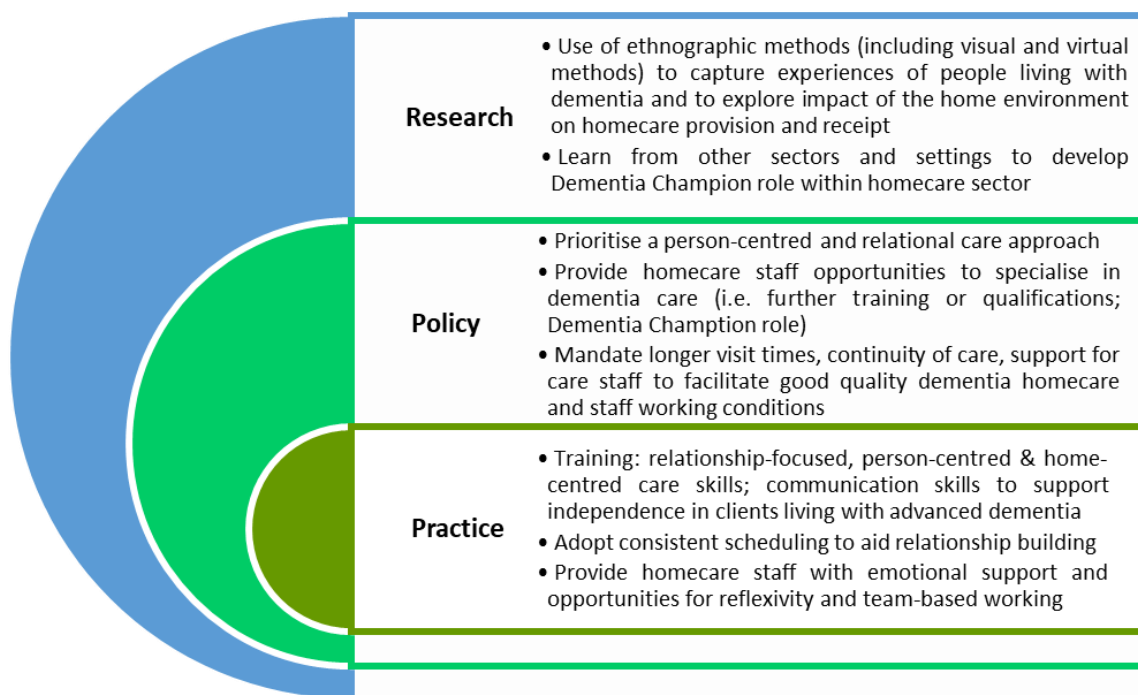
Figure 9.3: Implications and key recommendations for future research, policy and practice

9.7.1   Research

My research demonstrates the value of ethnographic methods of data collection, as an inclusive approach for future research exploring homecare for people living with dementia. Ethnographic methods such as participant observations enabled the experiences of people living with dementia to be captured, including those with more severe dementia. My use of visual methods, such as the sketches and photographs, enriched data collection and aided dissemination by increasing accessibility to audiences beyond academia (Heath et al., 2018; Prosser & Loxley, 2008). Whilst my idea to create sketches and take photographs came as a 'hunch' (Pink, 2020) after the start of data collection, future research planning to use visual methods from the point of study conception will enable a consistent approach amongst researcher-observers.

Participant observations of homecare highlighted important and novel considerations about the home environment and the way homecare workers interact with the home, that are important for future research to focus on more closely. The

impact of the built environment on people living with dementia has been studied in residential settings (Leung, Wang, & Chan, 2019), as well as day centres and acute care settings (Brown, 2020; Marquardt, 2020), but less is known about the impact of the home environment on homecare provision. A gap in knowledge therefore exists and future research may wish to adopt ethnographic methods, which I have shown lend themselves well to studying the impact of the home environment on homecare for people living with dementia. There is growing interest in developing 'dementia-ready', accessible housing (Twyford & Porteus, 2021, p. 9), yet this project remains in the planning stage and thus concerns the somewhat distant future, rather than addressing the needs of people who currently live at home with dementia and those who will need support in the near future. As the environments in which people live with dementia continue to evolve, it is important to understand how interactions with the environment work in practice to enable better care provision and working conditions.

Since I completed my fieldwork, the COVID-19 pandemic has increased the use of virtual/digital ethnographic methods (also termed cyber-ethnography) (Hine, 2008; Marres, 2017); when conducting participant observations in a time where travel and social contact are largely restricted, the 'field' has migrated to cyberspace (Krause et al., 2021; Watson, Lupton, & Michael, 2020). Such research may increasingly contribute to ethnographic methods post-pandemic, as we learn from their usage during the pandemic, and the proportion of older people who have digital access continues to grow.

Moreover, my findings add to a small yet growing body of research around training and support for homecare workers. While there is an understanding of what skills should be developed in a training programme and the support that homecare workers need (Polacsek et al., 2020; Schneider et al., 2019; Turner et al., 2018), it is less clear how to incorporate this into the current practices of homecare support for people living with dementia in England. The development of a pragmatic training and support intervention for homecare workers caring for people living with dementia is currently being tested and evaluated through the NIDUS programme, but there remains a gap in how to increase homecare workers' position and status as of equal

value, within the wider multidisciplinary network of health and social care professionals. Pertaining to my work, future research may wish to focus on developing and implementing the role of Dementia Champions within the homecare sector, by learning from how this role is implemented and utilised in other sectors and settings, both in the UK and internationally.

9.7.2 Policy

Training and support must be considered within the wider context and challenges of adult social care. There are potential longer-term benefits of investing in dementia-specific training for homecare staff, as well as providing structural support for homecare work, for example through funding longer visits for clients living with dementia. Enabling a more flexible way of providing care that is personalised and person-centred responds to the preferences of clients, family carers and homecare workers, and aligns with the relationship-focused and collaborative care approach that I identified as key to homecare for people living with dementia.

I considered above, the extent to which my findings supported arguments for professionalisation of the homecare workforce, and rights-based approaches for care staff to improve their general working conditions. There is scope to explore this further, for example, by learning from pioneering countries such as Sweden and Japan, where there has been an organisational shift towards professionalisation of the homecare workforce.

Moreover, I considered the role of Dementia Champions in homecare services; a role already established in NHS and care home settings. This has the potential to respond to the Government's call to make homecare an 'attractive profession' (Department of Health, 2015c), by enabling staff to develop and specialise within their role.

9.7.3 Practice

I highlighted both the importance of, and the complexities around the close relationships that developed between homecare workers, their clients and family carers. Homecare workers struggled to autonomously navigate these relationships within the professional boundaries of the role, and a lack of care continuity and direct

communication between homecare workers and family carers caused frustration. It is therefore important for training to equip homecare workers with the ability to skilfully deliver relationship-focused, person-centred, and home-centred care, and to confidently communicate with and meaningfully support independence in people living with advanced dementia.

There is consensus in my research and other work that team-based training and working is beneficial for care staff (Manthorpe et al., 2019; Yeh et al., 2018). It may be beneficial for homecare workers to have opportunities to engage in team-based learning and reflective practice, and for homecare agencies to explore how to implement this within current training paradigms and existing homecare practice. Moreover, many homecare workers reported experiencing grief when clients died. I identified the importance of emotional support provided by homecare managers and opportunities for peer support. Since I completed my fieldwork, the loss of clients and experience of grief are likely to have been heightened in the COVID-19 pandemic. Beyond training, it is important for homecare agencies to have appropriate practices in place to support the emotional needs of homecare workers, for example, drawing upon evidence-based models of supervision and facilitating opportunities for both formal and informal support.

9.7.3.1 The impact of COVID-19

I completed my data collection prior to the COVID-19 pandemic, which has had a profound impact on health and social care globally. COVID-19 posed a particularly high risk to people aged over 70 and those with underlying comorbidities (Clark et al., 2020). Most people living with dementia are included in these categories. People living with dementia were particularly affected by the restrictions (Nils, 2020) and lack of understanding about the situation. The use of Personal Protective Equipment (PPE) by care staff created additional challenges to communication and mood for people living with dementia (Woolham, Samsi, Norrie, & Manthorpe, 2020). Many families chose to discontinue their homecare because of concerns around virus transmission (Giebel et al., 2020).

The COVID-19 pandemic has undoubtedly shone light on the value of homecare workers to society (Giebel et al., 2020; Woolham et al., 2020). Care workers received little recognition or reward for their role prior to the pandemic, yet are now considered amongst the rhetoric of the 'keyworkers' and 'heroes' of society. Research has begun to explore experiences of healthcare workers (Cox, 2020; Hennekam, Ladge, & Shymko, 2020) and social care workers (McFadden et al., 2021) during the pandemic. This emerging evidence will hopefully inform how policy and practice can develop post-pandemic and improve the working conditions of the social care workforce.

As part of their pandemic response, the Department of Health and Social Care (2020) set out to recruit an additional 20,000 people into the social care workforce in England, targeting sector returners and new starters. Access to free training has since become available via Skills for Care, in addition to the Care Certificate, to enable rapid online induction training for new staff; although the uptake rate is not yet known. However, if financial pressures continue to be placed upon the homecare sector in a post-pandemic society, the focus on lowering costs will continue to be at the expense of homecare workers' psychological and physiological burden, and subsequently care quality for people living with dementia (Cunningham, Cowie, & Methven, 2020).

Chapter 10 Conclusions

I have ethnographically explored homecare for people living with dementia, considering the training and support needs of homecare workers and how they can be enabled to support independence in people living with dementia. Ethnographic methods, such as participant observations, are well suited to studying homecare, yet existing literature is sparse around the design and conduct of such methods, particularly for people living with dementia. My systematic review contributed to this literature and informed the design of my participant observations, carried out in my ethnographic study alongside qualitative interviews.

My ethnographic work highlighted the significance of the home for people living with dementia. I therefore posit that care that is person-centred is also home-centred, respecting the familiarity of the client's home as an extension of self. I found that training and support for homecare workers does not normally appear to address the key relational, emotional and rights-based aspects of the role. Where a responsive, person-centred and relationship-focused care service is desired by clients living with dementia, family carers and homecare staff, training has the potential to enable homecare workers to achieve this, whilst feeling secure and supported in doing so within a professional framework.

I have argued that by establishing interdependent and collaborative homecare relationships, homecare workers can facilitate people living with dementia to live as independently as possible, facilitating them to actively partake in daily tasks and meaningful decision-making. However, I found that providing person-centred care and involving clients living with more advanced dementia in meaningful decision-making was less well understood by homecare workers. While homecare workers may be well positioned to advocate for their clients living with dementia, there was little scope for homecare workers to participate in clients' care planning, with some feeling disempowered to advocate for their clients as part of the multidisciplinary care team. Homecare workers often worked in isolation, without their own workplace. I identified that the role of agency managers was crucial in supporting the

emotional and practical needs of homecare workers, i.e., through facilitating opportunities for both formal and informal peer and managerial support.

Furthermore, my work responds to calls for policy makers to improve and provide dementia-specific training for homecare workers. I considered policy implications from a rights-based approach: the rights of people living with dementia to receive good quality care from a sufficiently trained workforce, and the rights of homecare workers to be equipped with the necessary skills via training, and with emotional and practical support. Homecare workers want recognition for the value of their work with people living with dementia. I considered where this may be achieved through better working conditions and opportunities to contribute as important advocates within the multidisciplinary care network. Alongside organisational practice-level change, professionalisation of the workforce may tackle some of the systemic challenges of the sector, including low pay, lack of support and poor staff retention. This is particular pertinent in light of the COVID-19 pandemic, in which homecare workers have been recognised as keyworkers; this recognition now needs to translate into policy and practice, harnessing the value of these workers through better training and support.

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Appendices

Appendix 1   Published systematic review

This review was published in *Health & Social Care in the Community* (Leverton et al., 2019)

[Redacted]

Appendix 2   Interview information sheet: people living with dementia

This information sheet detailing the qualitative interview study was provided to people living with dementia

Camden and Islington *NHS*
NHS Foundation Trust

UCL

University College London
Division of Psychiatry
Maple House, 6th Floor Wing A
London W1T 7BN
Tel: 0207 6799031

Participant Information Sheet

Qualitative study exploring how people with dementia are supported to live independently at home: qualitative interview

We are inviting you to take part in a research project. We want to find out how best to support people living with dementia to be independent at home. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?
We want to find out how best to support people living with dementia to be independent at home.

Why have I been invited?
Because you are living with dementia in your own home, and you are a client of a home care agency or NHS team who are participating in this research study.

Do I have to take part?
No, it is up to you to decide. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone, we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed to take part if you decide to, and you will be given a signed copy to keep.

What will happen if I do not want to carry on with the study?

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we do not use any of the information you may have already given us. Any stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me if I take part?
A researcher will interview you about your experiences of living with dementia. We want to find out more about what enables people to live independently and what makes it more difficult.

What do I have to do?
If you agree to participate, you will be invited to talk to a researcher in a place you choose (we can come to your home or meet you at our centre) and asked to sign a consent form. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed or is at risk of serious harm. The researcher will take a few minutes to ask a few questions about your age, ethnicity, education and where you were born. These questions are because we want opinions from people from different backgrounds.

The discussion itself will last up to an hour, but we will be flexible and you are welcome to take breaks. It will be tape recorded so we make sure that we do not miss anything you say. We will ask you to discuss the ways in which you are or are not able to be independent, and to consider your priorities for help to maintain your independence. We will ask what has been helpful and unhelpful in supporting you to live independently.

We will type up the discussion and send it to you. You can make comments and corrections or add things if you wish but you do not have to. We will provide a stamped addressed envelope for you to return your comments to us if you wish to. We will also ask if we can contact you in the future to ask you to comment on what we have found out together from the discussions with everyone and our ideas about it.

Expenses and payments
We will give you a £20 voucher as a token of our appreciation for your time and trouble. We can also reimburse any travel costs if you prefer to travel to us for the interview upon submission of valid receipts.

What are the possible disadvantages and risks of taking part?
There are no right or wrong answers to the questions and you can talk about anything that you feel is relevant. It is possible that some topics discussed may be upsetting. If at any time during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on or stop the session altogether. If you feel upset by the interview you can speak to the researcher afterwards or ring the Alzheimer's Society National Helpline: 0300 222 1122. It is open from 9am to 5pm week days and 10am - 4pm at weekends.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get might help us develop ways to improve the wellbeing of people living with dementia who receive home care.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Page **2 of 4** | Participant Information Sheet for person with dementia with capacity; IRAS number 231047; version 2 (16/11/17)

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Will my taking part in the study be kept confidential?

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If the researchers observe what they consider to be poor care or neglect, they will discuss this with the relevant home care or NHS manager. If they remain concerned, or if at any time they find that someone is being harmed or at risk of harm, they will raise a safeguarding alert with the local social services. The audio-recording of the interview will be destroyed as soon as it has been transcribed by a professional transcription company that is contracted by UCL. You will not be personally identified in any publications. The information we collect will be stored on computers at UCL and University of Bradford, in a form in which you cannot be identified. We will keep your contact details separately for the duration of the study so we can contact you again when we need to for the study. Only study staff will have access to the data. We will delete the recording after it has been transcribed and checked. The transcript will be stored securely in accordance with UCL's archiving policy.

Contact

Please contact Dr Claudia Cooper, Principal Investigator or Alex Burton, programme manager on 0207679 9031 for further information. This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please read Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (Study Principal Investigator on 0207 6799031) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 17/0470. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?

The Alzheimer's Society are funding it, and University College London are organising it.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by RES Committee London – Camden and Kings Cross.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for taking time to read this sheet.

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Appendix 3   Interview information sheet: family carers

This information sheet detailing the qualitative interview study was provided to family carers of people living with dementia

Camden and Islington NHS
NHS Foundation Trust

UCL

University College London
Division of Psychiatry
Maple House, 6th Floor Wing A
London, W1T 7BN
Tel: 0207 679 9031

Participant Information Sheet

Qualitative study exploring how people with dementia are supported to live independently at home: qualitative interview

We are inviting you to take part in a research project. We want to find out how best to support people living with dementia to be independent at home. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1
What is the purpose of the study?
We want to find out the best ways to support people living with dementia to be independent at home.

Why have I been invited?
Because someone you know is living with dementia in their own home, and is client of a home care agency or NHS team that is participating in this research study.

Do I have to take part?
No. It is up to you to decide. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone, we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed to take part and you will be given a signed copy to keep.

What will happen if I do not want to carry on with the study?

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me if I take part?
A researcher will interview you about your experiences and those of the person you know who is living with dementia. We want to find out more about what enables people to live independently and what makes it more difficult.

What do I have to do?
If you agree to participate, you will be invited to talk to a researcher in a place you choose (we can come to your home or meet you at our centre) and asked to sign a consent form. We respect confidentiality but cannot keep it a secret if anyone is being seriously harmed or is at risk of serious harm. The researcher will take a few minutes to ask questions about your age, ethnicity, education and where you were born. These questions are because we want opinions from people from different backgrounds.

The discussion itself will last up to an hour, but we will be flexible about this and you are welcome to take breaks if you like. It will be tape recorded so we make sure that we do not miss anything. We will ask you to discuss the ways in which your relative/friend is and is not able to be independent, and what they and you feel are the important priorities for them that will help them maintain their independence. We will ask what support you have found to be helpful or unhelpful in supporting them to live independently.

We will type up the discussion and send it to you. You can make comments and corrections or add things if you wish but you do not have to. We will provide a stamped addressed envelope for you to return your comments to us if you wish to. We will also ask if we can contact you in the future to ask to comment on what we have found out together from the discussions with everyone and our ideas about it.

Expenses and payments
We will give you a £20 voucher as a token of our appreciation for your time and trouble. We can also reimburse any travel costs, or additional care costs if you need to employ a carer to look after the person you look after while you are taking part in the study upon submission of valid receipts.

What are the possible disadvantages and risks of taking part?
We do not foresee there being risks associated with the study. There are no right or wrong answers to the questions and you can talk about anything that you feel is relevant. It is possible that some topics discussed may be upsetting if, for example, the person you are looking after is finding it difficult to be independent or is distressed. If at any time during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on to another subject or leave the session altogether. If you feel upset by the interview you can speak to the researcher afterwards or ring the Alzheimer's Society National Helpline: 0300 222 1122. It is open from 9am to 5pm week days and 10am - 4pm at weekends.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help us develop ways to improve the wellbeing of people living with dementia who receive home care.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If the researchers observe what they consider to be poor care or neglect, they will discuss this with the relevant home care or NHS manager. If they remain concerned, or if at any time they find that someone is being harmed or at risk of harm, they will raise a safeguarding alert with the local social services. The audio-recording of the interview will be destroyed as soon as it has been transcribed by a professional transcription company that is contracted by UCL. You will not be personally identified in any publications. The information we collect will be stored on computers at UCL and University of Bradford, in a form in which you cannot be identified. We will keep your contact details separately for the duration of the study so we can contact you again when we need to for the study. Only study staff will have access to the data. We will delete the recording after it has been transcribed and checked. The transcript will be stored securely in accordance with UCL's archiving policy.

Contact
Please contact Dr Claudia Cooper, Principal Investigator or Alex Burton, programme manager on 0207 679 9031 for further information. This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please read Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (Study Principal Investigator on 0207 679 9031) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 17/0470. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?
The Alzheimer's Society are funding it, and University College London are organising it.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by RES Committee London – Camden and Kings Cross.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for taking time to read this sheet.

Appendix 4   Interview information sheet: care professionals

This information sheet detailing the qualitative interview study was provided to health and social care professionals and to homecare staff, including managers, office support staff and homecare workers

Camden and Islington **NHS**
NHS Foundation Trust

UCL

University College London
Division of Psychiatry
Maple House, 6th Floor Wing A
London, W1T 7BN
Tel: 0207 679 9031

Participant Information Sheet

Qualitative study exploring how people with dementia are supported to live independently at home: qualitative interview

We are inviting you to take part in a research project. We want to find out how best to support people living with dementia to be independent at home. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1
What is the purpose of the study?
We want to find out the best ways to support people living with dementia to be independent at home.

Why have I been invited?
Because you are a professional working for a home care agency or NHS team that is participating in this research study, and you provide care or treatment for people living with dementia.

Do I have to take part?
No. It is up to you to decide. Please read this information sheet carefully and think about any concerns you may have. If you agree to see us or want to talk on the phone, we can discuss the study in more detail with you and answer any questions or concerns you may have. We will then ask you to sign a consent form to show you have agreed to take part if you decide to do so, and you will be given a signed copy to keep. Your employment will not be affected if you decide not to take part.

What will happen if I do not want to carry on with the study?

You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Stored data that can still be identified as yours will be destroyed if you wish.

What will happen to me if I take part?
A researcher will interview you about your experiences and those of the people you know who live with dementia. We want to find out more about what enables people to live independently and what makes it more difficult.

What do I have to do?
If you agree to participate, you will be invited to talk to a researcher in a place you choose (we can come to your place of work or meet you at our centre) and asked to sign a consent form. We respect confidentiality but cannot keep it a secret is anyone is being seriously harmed or is at risk of serious harm. The researcher will spend a few minutes asking questions about your age, ethnicity, education and where you were born. These questions are because we want opinions from people from different backgrounds.

The discussion itself will last up to an hour and be tape recorded so we make sure that we do not miss anything. We will ask you to think of people living with dementia you know and discuss the ways in which they are or are not able to be independent, and what they and you feel is helpful and unhelpful in supporting them to maintain their independence.

We will type up the discussion and send it to you. You can make comments and corrections or add things if you wish but you do not have to. We will provide a stamped addressed envelope for you to return your comments to us if you wish to. We will also ask if we can contact you in the future to ask to comment on what we have found out together from the discussions with everyone and our ideas about it.

Expenses and payments
We will give you a £20 voucher as a token of our appreciation for your time and trouble if you undertake the interview in your own time (upon submission of valid receipts), or reimburse your employer for the time you spent taking part during your working day (up to £20 for the hour interview).

What are the possible disadvantages and risks of taking part?
There are no right or wrong answers to the questions and you can talk about anything that you feel is relevant. It is possible that some topics discussed may be upsetting. If at any time during the interview you find a topic sensitive or upsetting you can ask the interviewer to move on or stop the session altogether. If you feel upset by the interview you can speak to the researcher afterwards or ring the Alzheimer's Society National Helpline: 0300 222 1122. It is open from 9am to 5pm week days and 10am - 4pm at weekends.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get might help us develop ways to improve the wellbeing of people living with dementia who receive home care.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If the researchers observe what they consider to be poor care or neglect, they will discuss this with the relevant home care or NHS manager. If they remain concerned, or if at any time they find that someone is being harmed or at risk of harm, they will raise a safeguarding alert with the local social services. The audio-recording of the interview will be destroyed as soon as it has been transcribed by a professional transcription company that is contracted by UCL. You will not be personally identified in any publications. The information we collect will be stored on computers at UCL and University of Bradford, in a form in which you cannot be identified. We will keep your contact details separately for the duration of the study so we can contact you again when we need to for the study. Only study staff will have access to the data. We will delete the recording after it has been transcribed and checked. The transcript will be stored securely in accordance with UCL's archiving policy.

Contact

Please contact Dr Claudia Cooper, Principal Investigator or Alex Burton, programme manager on 0207 679 9031 for further information. This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please read Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (Study Principal Investigator on 0207 679 9031) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 17/0470. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?

The Alzheimer's Society are funding it, and University College London are organising it.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by RES Committee London – Camden and Kings Cross.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for taking time to read this sheet.

Appendix 5   Interview consent form: people with dementia/family carers

This consent form relating to the qualitative interview study was completed by people living with dementia and family carers

Camden and Islington **NHS**
NHS Foundation Trust

UCL

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Exploring how people with dementia are supported to live independently at home: qualitative study

Name of Researchers: Claudia Cooper, Alexandra Burton, Penny Rapaport, Monica Leverton, Ruminda Herat

Please initial box

1. I confirm that I have read the information sheet dated 16/11/17 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected.

3. I agree for my interviews to be audiotaped I understand that all material and personal information will be kept in accordance with the UCL Records Management Policy.

4. I agree to be contacted again and asked if I would like to give an opinion about the findings and the team's use of them.

5. I agree that I can be quoted as long as the quotes are anonymous.

6. I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

7. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers

8. I agree to take part in the above study

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking consent

Appendix 6 Interview consent form: care professionals

This consent form relating to the qualitative interview study was completed by health and social care professionals and homecare staff, including managers, office support staff and homecare workers.

⌐UCL

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Exploring how people with dementia are supported to live independently at home: qualitative study

Name of Researchers: Claudia Cooper, Alexandra Burton, Penny Rapaport, Monica Leverton, Ruminda Herat

Please initial box

1. I confirm that I have read the information sheet dated 16/11/17 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal or medical rights being affected.

3. I agree for my interviews to be audiotaped I understand that all material and personal information will be kept in accordance with the UCL Records Management Policy.

4. I agree to be contacted again and asked if I would like to give an opinion about the findings and the team's use of them.

5. I agree that I can be quoted as long as the quotes are anonymous.

6. I understand that relevant data collected during the study, may be looked at by individuals from UCL, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

7. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers

8. I agree to take part in the above study

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking consent

Consent form, home carer; IRAS number 231047; version 1 (08/08/17) page 1 of 1

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Appendix 7   Observation information sheet: homecare agencies

This information sheet relating to the participant observation study was provided to homecare agency managers.

University College London,
Division of Psychiatry,
Maple House, 6th Floor Wing A,
London W1T 7BN.
Tel: 0207 6799031

Participant Information Sheet

Qualitative study exploring how people with dementia are supported to live independently at home: non-participant observation study

We are inviting you to take part in a research project. We want to find out how home care services can best support people living with dementia to be independent at home. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1
What is the purpose of the study?
We want to find out the best ways that home care services can support people living with dementia to be independent at home.

Why have I been invited?
Because you manage a service that provides care to clients living with dementia.

Do I have to take part?
No. It is up to you to decide whether to take part. You are free to withdraw any time without giving a reason. If you do it will not affect your employment in any way.

What will happen to me if I take part?
A researcher will ask you invite home carers who work in your agency, their clients who have dementia and their family carers if they are present during visits to take part in the study. Researchers will accompany those home carers who agree during some of their shifts over 3-4 months. Initially, the researcher will not be making notes, as the purpose will be to get to know the carer, and those of their clients and their families who agree to be in the study, so that everyone feels comfortable. For up to five of the visits with each client towards the end of their time observing, the researcher will be making notes to record details of the home care

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visit, such as the care provided, client's reactions to it and interactions with clients and others present. They will also observe their discussions with you, their manager.

Expenses and payments

We will reimburse your employer for the time you spent taking part during your working day (up to £20 per hour).

What do I have to do?

You will not be asked to answer any questions or take part in an interview. A researcher will observe as you interact with participating home carers. We will ask you to approach staff, clients and their family carers, and give them an information sheet about the study.

What are the possible disadvantages and risks of taking part?

The researcher will seek to observe as unobtrusively as possible. If at any time you, you or another staff member wants the researcher to leave or cease observations for a time they will do so immediately. If taking part brings up issues that you would like to talk about you can ask speak to one of our team. You may also find the Alzheimer's Society National Helpline: 0300 222 1122. It is open from 9am to 5pm week days and 10am - 4pm at weekends.

What are the possible benefits of taking part?

We cannot promise the study will help you or your clients, but the information we get might help us develop ways to improve the wellbeing of people living with dementia who receive home care. We will reimburse you and your staff for time spent directly assisting the study.

What if I do not want to carry on with the study?

If at any time you want the researcher to leave they will do so immediately. You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Stored data that can still be identified as yours will be destroyed if you wish.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If the researchers observe what they consider to be poor care or neglect, they will discuss this with the relevant home care or NHS manager. If they remain concerned, or if at any time they find that someone is being harmed or at risk of harm, they will raise a safeguarding alert with the local social services. You will not be personally identified in any publications. The information we collect will be stored on computers at UCL and University of Bradford, in a form in which you cannot be identified. We will keep your contact details separately for the duration of the study so we can contact you again when we need to for the study. Only study staff will have access to the data.

Contact

Please contact Dr Claudia Cooper, Principal Investigator or Alex Burton, Programme Manager on 02076799031 for further information. This completes Part 1 of the Information

Sheet. If the information in Part 1 has interested you and you are considering participation, please read Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (Study Principal Investigator on 0207 6799031) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing,Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 17/0470. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?

We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?

The Alzheimer's Society are funding it, and University College London are organising it.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by RES Committee London – Camden and Kings Cross.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for taking time to read this sheet.

Appendix 8   Observation consent form: homecare managers

This consent form relating to the participant observation study was completed by homecare managers who gave consent for their agency to be involved in the research.

⌂UCL

Centre Number:

Study Number:

Participant Identification Number:

CONSENT FORM, home care agency manager

Exploring how people with dementia are supported to live independently at home: non-participant observation study

Name of Researcher: Dr Claudia Cooper

Please initial box

1. I confirm that I have read the information sheet dated 13/11/17 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

4. I agree to a researcher taking photographs of the home care agency environment. I understand that these photographs will not contain identifiable information such as people, names or logos. ☐

5. I agree to take part in the above study. ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature

Participant consent form for home care manager, IRAS number 231047; version 1 (25/08/17) page 1 of 1

Appendix 9   Observation information sheet: homecare workers

This information sheet relating to the participant observation study was provided to homecare workers.

UCL

University College London,
Division of Psychiatry,
Maple House, 6th Floor Wing A,
London W1T 7BN.
Tel: 0207 679 9031

Participant Information Sheet

Qualitative study exploring how people with dementia are supported to live independently at home: non-participant observation study

We are inviting you to take part in a research project. We want to find out how home care services can best support people living with dementia to be independent at home. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1
What is the purpose of the study?
We want to find out the best ways that home care services can support people living with dementia to be independent at home.

Why have I been invited?
Because you provide care to clients living with dementia in your work at a home care agency that is participating in this research study.

Do I have to take part?
No. It is up to you to decide whether to take part. You are free to withdraw any time without giving a reason. If you do it will not affect your employment in any way.

What will happen to me if I take part?
A researcher will accompany you during some of your shifts over 3-4 months. Initially, the researcher will not be making notes, as the purpose will be to get to know you, and those of your clients and their families who agree to be in the study, so that everyone feels comfortable. For up to five of the visits towards the end of their time observing, the researcher will be making notes to record details of the home care visit, such as the care provided, client's reactions to it and interactions with clients and others present.

Participant Information Sheet for paid carer; IRAS number 231047; version 2 (13/11/17)

Expenses and payments

We will reimburse your employer for the time you spent taking part during your working day (up to £20 per hour).

What do I have to do?

You will not be asked to answer any questions or take part in an interview. A researcher will travel with you during your shift and observe as you provide care to those clients who are part of the study, or interact with managers and other staff. We will ask you to approach clients and their family carers to invite them to take part and give them an information sheet about the study. We will ask you to update us about any important information we should know about clients before visits in order to be sensitive when observing.

What are the possible disadvantages and risks of taking part?

The researcher will seek to observe as unobtrusively as possible. We would like observations to include all aspects of care, including personal care where this is usually provided as this is an important part of home care. If at any time you, your client or a family member wants the researcher to leave or cease observations for a time they will do so immediately. If taking part brings up issues that you would like to talk about you can ask speak to one of our team. You may also find the Alzheimer's Society National Helpline: 0300 222 1122. It is open from 9am to 5pm week days and 10am - 4pm at weekends.

What are the possible benefits of taking part?

We cannot promise the study will help you or your clients, but the information we get might help us develop ways to improve the wellbeing of people living with dementia who receive home care. We will reimburse your agency for time you or other spend directly assisting the study.

What if I do not want to carry on with the study?

If at any time you want the researcher to leave they will do so immediately. You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Stored data that can still be identified as yours will be destroyed if you wish.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If the researchers observe what they consider to be poor care or neglect, they will discuss this with the relevant home care or NHS manager. If they remain concerned, or if at any time they find that someone is being harmed or at risk of harm, they will raise a safeguarding alert with the local social services. You will not be personally identified in any publications. The information we collect will be stored on computers at UCL and University of Bradford, in a form in which you cannot be identified. We will keep your contact details separately for the duration of the study so we can contact you again when we need to for the study. Only study staff will have access to the data.

Contact
Please contact Dr Claudia Cooper, Principal Investigator or Alex Burton, Programme Manager on 0207 6799031 for further information. This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please read Part 2 before making any decision.

Part 2

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (Study Principal Investigator on 0207 6799031) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing, Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 17/0470. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?
The Alzheimer's Society are funding it, and University College London are organising it.

Who has reviewed the study?
All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by RES Committee London – Camden and Kings Cross.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for taking time to read this sheet.

Appendix 10   Observation consent form: homecare workers

This consent form relating to the participant observation study was completed by homecare workers in participating homecare agencies.

UCL

Centre Number:

Study Number:

Participant Identification Number:

CONSENT FORM, home carer

Exploring how people with dementia are supported to live independently at home: non-participant observation study

Name of Researcher: Dr Claudia Cooper

Please initial box

1. I confirm that I have read the information sheet dated 13/11/2017 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

4. I agree to take part in the above study.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking consent

Appendix 11   Observation information sheet: people living with dementia

This information sheet relating to the participant observation study was provided to people living with dementia, with capacity to consent to taking part in the research.

Participant Information Sheet

<u>Qualitative study exploring how people with dementia are supported to live independently at home: non-participant observation study</u>

We are inviting you to take part in a research project. We want to find out how home care services can best support people living with dementia to be independent at home. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?
We want to find out the best ways that home care services can support people living with dementia to be independent at home.

Why have I been invited?
Because you are a client of a home care agency that is participating in this research study, and you are living with dementia.

Do I have to take part?
No. It is up to you to decide whether to take part. You are free to withdraw any time without giving a reason. If you do it will not affect the care you receive in any way.

What will happen to me if I take part?
A researcher will be accompanying your home carer during some of his/her shifts over 3-4 months. Initially, the researcher will not be making notes, as the purpose will be to get to know you and the home carer so that everyone feels comfortable. For up to five of the visits towards the end of their time observing, the researcher will be making notes to record details of the home care visit, such as they provide care to you and talk with you and others present. You will receive a £20 voucher as a thank you for taking part.

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What do I have to do?

You will not be asked to answer any questions or take part in an interview. You will be asked to sign a consent form. A researcher will be present during home visits in which your carer visits you, and we are asking for your permission for the researcher to observe your interactions with the home care staff and others present during visits, for example family members.

What are the possible disadvantages and risks of taking part?

The researcher will seek to observe as unobtrusively as possible. We would like observations to include all aspects of care, including personal care where this is usually provided as this is an important part of home care. If taking part brings up issues that you would like to talk about you can ask speak to one of our team. You may also find the Alzheimer's Society National Helpline: 0300 222 1122. It is open from 9am to 5pm week days and 10am - 4pm at weekends.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help us develop ways to improve the wellbeing of people living with dementia who receive home care.

What if I do not want to carry on with the study?

If at any time you want the researcher to leave they will do so immediately. You are free to withdraw from the study at any time, without giving a reason. If you withdraw from the study, you can also request that we not use any of the information you may have already given us. Stored data that can still be identified as yours will be destroyed if you wish.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If the researchers observe what they consider to be poor care or neglect, they will discuss this with the relevant home care or NHS manager. If they remain concerned, or if at any time they find that someone is being harmed or at risk of harm, they will raise a safeguarding alert with the local social services. You will not be personally identified in any publications. The information we collect will be stored on computers at UCL and University of Bradford, in a form in which you cannot be identified. We will keep your contact details separately for the duration of the study so we can contact you again when we need to for the study. Only study staff will have access to the data.

Contact

Please contact Dr Claudia Cooper, Principal Investigator or Alex Burton, Programme Manager on 0207 6799031 for further information. This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please read Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (Study Principal Investigator on 0207 6799031) who will do her best to answer your questions. If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing,Ground Floor, 25 Grafton Way, London WC1E 5DB quoting study 17/0470. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you would like a copy of any publications and we would be happy to send them to you when they are published. You will not be identified in any report/publication.

Who is organising and funding the research?
The Alzheimer's Society are funding it, and University College London are organising it.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by RES Committee London – Camden and Kings Cross.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for taking time to read this sheet.

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Appendix 12   Observation consent form: people living with dementia

This consent form relating to the participant observation study was completed by people living with dementia, with capacity to consent to taking part in the research.

≜UCL

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM, Person living with dementia

Exploring how people with dementia are supported to live independently at home: non-participant observation study

Name of Researcher: Dr Claudia Cooper

Please initial box

1. I confirm that I have read the information sheet dated 13/11/17 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

5. I agree to take part in the above study.

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person   Date   Signature
taking consent

Participant consent form for person with dementia, IRAS number 231047; version 1 (08/08/17) Page 1 of 1

Appendix 13   Observation information sheet: consultees

This participant information sheet relating to the participant observation study was provided to a personal or nominated consultee, where the person living with dementia did not have capacity to consent to the research.

UCL

University College London,
Division of Psychiatry,
Maple House, 6th Floor Wing A,
London W1T 7BN. Tel: 0207 6799031

Nominated consultee Information Sheet

Qualitative study exploring how people with dementia are supported to live independently at home: non-participant observation study

You are being invited to act as a 'consultee' for someone who is unable to make a decision for him/herself. You are being asked to advise the researcher about this person's wishes and feelings and whether they would have wished to join this research. Please let us know of any advance decisions they may have made about participating in research. Before you decide, it is important you understand what being a consultee means, why the research is being done and what it will involve. Please take time to read this information carefully and talk to others about the study if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide whether you wish to be a consultee.

What does it mean to be a consultee?

A consultee is someone who is willing and able to offer an opinion on what that person's wishes would have been if they were still able to decide themselves whether to take part. You do not have to act as a consultee if you do not want to. If you are unsure about taking on the role of consultee you may seek independent advice. If you decide to act as consultee, you will be asked to sign a Consultee Declaration Form. If in your opinion the person we are asking you about would not have wanted to take part, then the researchers will respect this and it will not affect the standard of care they receive in any way. Please remember that you are not being asked for your personal views on the research, but only your opinion of this person's wishes about taking part in the study. Think about the risks and benefits and what taking part will mean for this person.

Why have I been asked to be a consultee?

You are being asked because you are a senior, experienced health or social care professional who is not directly involved in the research or care of the person we are asking you about, who does not have a family member or friend who is available to make this decision on their behalf.

The following information is the same as that which has been provided to the person you are advising us about.

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About the study

We are inviting the person we are asking you about to take part in this research project. We want to find out how home care services can best support people living with dementia to be independent at home. Before you decide whether in your opinion the person we are asking you about would want to take part, it is important that you understand why the research is being done and what the study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

- Part 1 tells you the purpose of this study and what will happen to the person you are advising us about if they take part.
- Part 2 gives you more detailed information about the conduct of this study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you think the person you are advising about would want to take part.

Part 1

What is the purpose of the study?
We want to find out how home care services can best support people living with dementia to be independent at home.

Why has the person we are asking you about been invited?
Because they are a client of a home care agency that is participating in this research study and they are living with dementia.

What will happen if I decide the person would not want to carry on with the study?

You are free at any point to request that this person is withdrawn from the study without giving a reason. This would not affect their care in any way. If they are withdrawn from the study, you can request that we do not use any of the information they have already given us. Any stored data that can still be identified as theirs will be destroyed if you or they wish.

Does the person we are asking you about have to take part?
No. It is up to you to advise us whether or not he/she would have wanted to take part. You will be given the information sheet to keep.

What will happen to them if they take part?
A researcher will be accompanying the home carer who visits the person we are asking you about during some of his/her visits over 3-4 months. Initially, the researcher will not be making notes, as the purpose will be to get to know this person and their home carer so that everyone feels comfortable. For up to five of the visits towards the end of the observation time, the researcher will be making notes to record details of the home care visit, such as how the carer provides care and talk to the person we are asking you about and others present. The person we are asking you about will receive a £20 voucher as a thank you for taking part.

What does the person we are asking you about have to do?
They will not be asked to answer any questions or be interviewed. A researcher will be present during home visits in which their home carer visits them, and the researcher will

observe the interactions of the participating client and the home care staff and others present during visits, for example family members.

What are the possible disadvantages and risks of taking part?

The researcher will seek to observe as unobtrusively as possible. We would like observations to include all aspects of care, including personal care where this is usually provided as this is an important part of home care. If at any time the participant or anyone else present wants the researcher to leave they will do so immediately. If taking part brings up issues that the participant would like to talk about he/she can ask speak to one of our team. He/she may also find the Alzheimer's Society National Helpline helpful: 0300 222 1122. It is open from 9am to 5pm week days and 10am - 4pm at weekends.

What are the possible benefits of taking part?
We cannot promise the study will help clients who participate, but the information we get might help us develop ways to improve the wellbeing of people living with dementia who receive home care.

What if there is a problem?
Any complaint about the way the participant has been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
We respect confidentiality but cannot keep it a secret if anyone is being harmed or is at risk of any harm. If the researchers observe what they consider to be poor care or neglect, they will discuss this with the relevant home care or NHS manager. If they remain concerned, or if at any time they find that someone is being harmed or at risk of harm, they will raise a safeguarding alert with the local social services. The participant will not be personally identified in any publications. The information we collect will be stored on computers at UCL and University of Bradford, in a form in which they cannot be identified. We will keep the person's contact details separate to other information collected for the duration of the study so we can contact them again when we need to for the study. Only study staff will have access to the data.

Contact
Please contact Dr Claudia Cooper, Principal Investigator or Alex Burton Programme Manager on 0207 6799031 for further information. This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering that the person we are asking you about might want to take part, please read Part 2 before making any decision.

Part 2

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak with Dr Claudia Cooper (Study Principal Investigator on 0207 6799031) who will do her best to answer your questions. If you remain unhappy and you or the person we are asking you about wish to complain formally about any aspect of the way you or he/she have been approached or treated during the course of this study, you may contact the Research Governance Sponsor of this study, University College London. Please write to UCLH/UCL Joint Biomedical Research Unit, R&D Directorate, Roseheim Wing,Ground Floor, 25 Grafton

Way, London WC1E 5DB quoting study 17/0470. In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against UCL but you may have to pay your legal costs.

What will happen to the results of the research study?
We intend to publish results in relevant conference proceedings and publications. Please tell the researchers if you or the person you are advising us about would like a copy of any publications and we would be happy to send them when they are published. Participants will not be identified in any report/publication.

Who is organising and funding the research?
The Alzheimer's Society are funding it, and University College London are organising it.

Who has reviewed the study?

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by RES Committee London – Camden and Kings Cross.

You will be given a copy of the information sheet and a signed consent form to keep. Thank you for taking time to read this sheet.

Appendix 14   Observation consent form: consultees

This consent form relating to the participant observation study was completed by a personal or nominated consultee, where the person living with dementia did not have capacity to consent to the research.

Centre Number:

Study Number:

Participant Identification Number:

CONSULTEE DECLARATION FORM

Exploring how people with dementia are supported to live independently at home: non-participant observation study

Name of Researcher: Dr Claudia Cooper; Monica Leverton

Please **initial** box

1. I..[   ] have been consulted about [   ]'s participation in this research project.
    I confirm that I have read the information sheet dated 13/11/17 (version 2) for the above study.
    I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that his/her participation is voluntary and that I am free to advise that they withdraw at any time without giving any reason, without their care or legal rights being affected.

    I understand that the information collected regarding he/she will be used to support other research in the future, and may be shared anonymously with other researchers.

4. I understand that information about their background details and medical condition will be obtained from the home care agency notes.

5. I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from UCL or from regulatory authorities, where it is relevant to taking part in this project.

6. In my opinion he/she would have no objection to taking part in the above study.

_____   _____   _____   _____
Name of Consultee   Relationship to participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking consent

Appendix 15   Observation questionnaire: homecare agencies

This demographics questionnaire was completed by homecare managers in the participant observation study, to provide information about their homecare agency.

1. Home carer information

When did the home care agency open? (dd/mm/yyyy)	
On the census date:	
How many home carers work at the branch?	
How many home carers do you employ on permanent contracts? **Full time** **Part time**	
What is the hourly pay rate for home carers? *If different rates for different services please specify*	
How many home carers are on zero hours contracts?	
How many agency/bank staff do you have?	
How many home carers are on sick/carer/ compassionate leave	
Over the last 6 months:	
How many home carers have joined the agency?	
How many home carers have left the agency?	

2. Client information

On the census date:	
How many clients are registered with the agency?	
Approximately how many clients have dementia/memory problems?	
How many private paying clients/contracts do you have?	
How many local authority paying clients do you have?	

3. Training

Do you provide dementia specific training?	
If yes is this accredited training?	
Who provides the training /what is the name of the course?	
How often do you provide dementia training?	
How many sessions of dementia specific care training are provided?	
On average, how long are the sessions?	
In the last 12 months:	
How many home care staff have received dementia training?	
Who received the training?	
Home carers	
Home care managers	
Case managers	
Other (Please list)	

This demographics questionnaire was completed by homecare workers taking part in the participant observation study.

Exploring how people with dementia are supported to live independently at home: The NIDUS (New Interventions for Independence in Dementia) study

Participant identification number   **Interview date**

D	D	M	M	Y	Y

1. **Job title** [   ]
2. **Date of birth** ……………………………………………………
3. **Sex** ☐ Male   ☐ Female   ☐ Other   ☐ Prefer not to say
4. **Self-assigned ethnicity:** *Please tick the appropriate box*

White	☐ British
	☐ Irish
	☐ White Other
Black/Black British	☐ Caribbean
	☐ African
	☐ Black Other
Asian/Asian British	☐ Indian
	☐ Pakistani
	☐ Bangladeshi
	☐ Chinese
	☐ Asian Other
	☐ Mixed *Please specify* ………………………………
	☐ Unable to specify
Other ethnic group: *Please specify* …………………………………………………………………………………	
	☐ Prefer not to say

5. Nationality ………………………………………………………………

6. What did you do before you became a Home Care Worker/ Manager?
………………………………………

7. a) Is your current employment: ☐ Full time ☐ Part time ☐ Other

     b) If part time: ……………………….hours per week

     c) If other, please specify: ……………………………………………………………………………….

     e.g. Zero hour contract

8. How long have you worked in care? *Please tick one box*

☐ Less than 6 months
☐ 6 months – 1 year
☐ 1-3 years
☐ 3-5 years
☐ 5-10 years
☐ 10 years or more
☐ Unable to specify

9. How long have you worked in this agency? *Please tick one box*
☐ Less than 6 months
☐ 6 months – 1 year
☐ 1-3 years
☐ 3-5 years
☐ 5-10 years
☐ 10 years or more
☐ Unable to specify

10. How do you travel between client homes?
☐ Bus   ☐ Tube/ Train   ☐ Car   ☐ Cycle   ☐ Walk

☐ Other ……………………………………………………………   ☐ Not applicable

11. Do you have personal experience of dementia?
☐ Yes
☐ No
☐ Prefer not to say

Appendix 17   Participant observation guide

This is the semi-structured participant observation schedule used to guide the researcher-observers in the participant observation study.

Home visit details (*complete a new sheet for each visit/observation*) and field notes guide for home carer/client observations

FIELD NOTE VISIT ………

Home carer ID: ……………………………

Client ID: ……………………………………

Observation visit date: ………………………….

Observation visit start time: ………… Observation visit end time: ……………

Researcher observing: …………………………..

Guidance: Areas of interest to keep in mind during the observation:

1. A practical overview of the visit
   a) record the time at which the home carer arrives and leaves the client's home
   b) who is present
   c) the environment in which the care is being delivered including physical layout, decor and cleanliness
   d) "atmosphere" including general feelings about tension, is it welcoming, comfortable etc
   e) the tasks that are delivered

2. Interactions and responses of home carers with clients and others

    a) interactions and responses between the home carer and the client with dementia

    b) interactions and responses between the home carer and others who may be present

        o *positive, negative and neutral interactions/responses*

        o *support of independence/ choice/ autonomy where possible*

        o *challenges to independence (e.g. symptoms of distress, refusal of care or risks) and responses to it where this occurs, and whether these strategies are effective in resolving distress and enabling necessary care to be given*

        o *emotional responses, strategies and resources used (e.g. practical, social, spiritual)*

    c) how client (including behaviour, language, ethnicity and culture), family carer, home carer and/or management and organisational factors impact on care provided

    d) whether additional needs arise, either stated by the person with dementia, family carer or home carer and how these are managed.

    e) references to client or family carer goals or priorities, how these emerge and how they are acknowledged or not.

    f) general thoughts and feelings about the care being delivered and how the care provided enables or disables independence

    g) how your presence as a non-participant observer may have influenced your observations

Appendix 18   Published training and support paper

This paper was published in *Dementia*: *The international Journal of Social Research and Practice* (Leverton et al., 2021b).

'You can't just put somebody in a situation with no armour'. An ethnographic exploration of the training and support needs of homecare workers caring for people living with dementia

Monica Leverton and **Alexandra Burton**
Division of Psychiatry, University College London, London, UK

Jules Beresford-Dent
Centre for Applied Dementia Studies, University of Bradford, Bradford, UK

Penny Rapaport
Division of Psychiatry, University College London, London, UK

Jill Manthorpe
NIHR Policy Research Unit on Health and Social Care Workforce, King's College London, London, UK

Hassan Mansour and Stefanny Guerra Ceballos
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Division of Psychiatry, University College London, London, UK

Abstract

Background: Homecare workers carry out complex work with people living with dementia, while under-supported, undervalued and undertrained. In this ethnographic study, we explore the skills, training and support needs of homecare workers supporting people living with dementia.

Research Design and Methods: We conducted 82 interviews with people living with dementia ($n = 11$), family caregivers ($n = 22$), homecare staff ($n = 30$) and health and social care professionals ($n = 19$) and conducted 100-hours of participant observations with homecare workers ($n = 16$). We triangulated interview and observational findings and analysed data thematically.

Results: We developed four themes: 1) 'Navigating the homecare identity and role': describing challenges of moving between different role identities and managing associated expectations, 2) 'Developing and utilising relational and emotional skills': boundaries between caring and getting emotionally involved felt blurred and difficult to manage, 3) 'Managing clients who resist care': homecare workers experienced clients' reactions as challenging and felt "thrown to the wolves" without sufficient training, and 4) 'Drawing on agency and team support': homecare work could be isolating, with no shared workplace, busy schedules and limited opportunity for peer support.

Discussion and Implications: It is important that training and support for homecare workers addresses the relational, emotional and rights-based aspects of the role. Where a flexible, responsive, person-centred service is required, corresponding training and support is needed, alongside organisational practices, taking account of the broader context of the homecare sector.

Background and objectives

There are 850,000 people living with dementia in the United Kingdom (Wittenberg et al., 2020) and over 46 million people globally (Prince et al., 2015). Over 680,000 paid care workers in England provide direct care to people in their own homes (Skills for Care, 2018). Two-thirds of these workers, termed homecare workers, direct care workers or domiciliary support workers regularly care for people living with dementia (Carter, 2016). The homecare sector is in increasingly high demand and will grow substantially as society ages and care shifts further to domiciliary settings, where most people with dementia prefer to remain living.

Over 9000 Care Quality Commission (CQC) regulated homecare providers operated across England in 2018 (Skills for Care, 2020). The vast majority are independent or voluntary organisations (UKHCA, 2016). Homecare workers are predominantly female (84%), white (76%) and British (83%), with an average age of 43 years (Skills for Care, 2019), similar to the wider adult

social care workforce. Most work part-time and 56% are employed on zero-hour contracts (Skills for Care, 2020). They form the largest proportion of paid staff in the home setting, delivering personal care, assistance with domestic activities, basic nursing care and companionship.

Homecare workers are the 'front line' of the social care system (The King's Fund, 2018). However, the sector faces challenges including poor recruitment, retention, low pay and morale (The King's Fund, 2018). Homecare workers receive limited to no supervision or training, the quality of their work is often publicly scrutinised and their value to clients living with dementia and their family members may be unrecognised.

Mandatory training was introduced as the Care Certificate in England, in 2015. Social care staff are expected to complete the Care Certificate during their induction (Skills for Care, 2015); however, it has not been taken up universally (Skills for Care, 2018). This may be related to the fact that it is not an accredited national qualification and employers are not obliged to offer it to staff. The Care Certificate contains minimal awareness training in relation to dementia, and there is currently no requirement for homecare workers to complete dementia-specific training; a third of English homecare workers have not received dementia training (Skills for Care, 2018). More dementia-specific training could improve homecare provision and in turn, it may improve client quality of life, reduce distressing behaviours (Surr et al., 2017) and subsequently may be cost-effective in supporting people with dementia to live at home for longer (Cooper et al., 2017). Developing such training requires the perspectives of all stakeholders involved in homecare provision, including clients living with dementia.

Ethnographic research methods are well-suited to exploring care at home (Briggs et al., 2003), particularly with people living with dementia (Leverton et al., 2019; MacLaren et al., 2017). Participant observations can capture the perspectives of those with more severe dementia, who may be unable to express verbally (Mansell, 2011). In the 'Broadening our Understanding of Good Home Care' (BOUGH) programme, researchers ethnographically explored the experiences of homecare workers supporting people living with dementia, from one commercial UK agency (Pollock et al., 2020; Schneider et al., 2019). Preserving and maintaining clients' physical, mental, emotional and social well-being was of paramount importance. Receiving recognition and feeling able to make even small improvements in clients' well-being were seen as part of the 'implicit moral balance' in homecare, highlighting the potential for reward and recognition to improve staff retention (Schneider et al., 2019). The authors emphasised the value of social skills; family carers prioritised homecare workers as companions for their relatives with dementia, beyond practical care tasks (Pollock et al., 2020). Therefore, understanding how to provide a holistic care approach with empathy for clients' preferences and social needs could potentially be developed through training, alongside support that enables homecare workers to feel valued in their role.

In the current study, we extended the existing evidence-base in a large ethnographic study encompassing several homecare agencies, including the perspective of clients living with dementia. Our methods provide a complementary perspective to the BOUGH study (Schneider et al., 2019), using researcher-observers to directly observe the practice of homecare workers. We took an ethnographic approach to explore our research question across perspectives of key stakeholders: what are the skills, training and support needs of homecare workers providing care for people living with dementia? This study informed the development of a coproduced training and support intervention for homecare workers in a wider programme of work (Lord et al., 2020).

Methods

Study design

We conducted a multi-site study of homecare for people living with dementia using an ethnographic approach. We held qualitative semi-structured interviews between April and August 2018 with people living with dementia, family carers, health and social care professionals and homecare staff. We undertook participant observations with homecare workers providing care to clients living with dementia between September 2018 and March 2019. Participant observation methods were informed by our earlier review of homecare observational studies (Box 1). We took a rapid ethnographic approach, prioritising breadth over depth (Utarini et al., 2001; Vindrola-Padros & Vindrola-Padros, 2018). We observed care in several agencies for a shorter time duration, as opposed to more intensive observations in one agency. This approach allows for greater generalisability and faster translation of research into practice (Knoblauch, 2005). As this study informed intervention development for the homecare sector, it was important to have a broad understanding across homecare agencies and stakeholder groups.

Setting and sample

Qualitative interviews. We recruited key stakeholders involved in homecare provision for people living with dementia. This included people diagnosed with dementia with capacity to consent and carers (relatives or friends) from three National Health Service (NHS) memory services, a private homecare agency, an Alzheimer's Society Experts by Experience group and Twitter. Health and social care professionals who were involved in commissioning or planning homecare for people living with dementia were recruited through UCL, four NHS memory services and one local authority. We recruited homecare staff from ten urban and semi-rural/rural homecare agencies, who worked with local authority and/or privately funded clients with dementia. Homecare staff included agency managers, office support staff and direct homecare workers. All gave written informed consent.

Participants were purposively recruited to include a range of ages, ethnicities, roles (homecare staff, health and social care professionals), relationship to the person with dementia (family carers), experience with homecare services (people living with dementia) and shift-pattern and client-type (homecare workers).

Participant observations. We purposively sampled homecare agencies for diversity of location (in urban or rural/semi-rural locations), CQC (regulator) rating and care provision (i.e. agencies with 15-minute visits and agencies with a one-hour minimum visit policy). We contacted agency managers to seek their agency's participation. Of the 11 homecare agencies participating in qualitative interviews, we purposively approached seven varied agencies to also take part in observations. Of these, one manager declined and another consented, but we lost contact with the agency after the manager moved. We approached three additional agencies that were not involved in the interviews. Of these, one manager agreed their agency could participate, and two other agency managers expressed preliminary interest that was not sustained.

Homecare agency managers were asked to complete a questionnaire about their agency and to direct us to homecare workers who supported client(s) living with dementia. We excluded staff intending to leave the agency within 6 months. We provided a participant information sheet, sought written consent and demographic information. Homecare workers and managers then invited clients diagnosed with dementia and their family members to participate. A nominated consultee (i.e.

Box 1. Methodological design considerations for conducting participant observations in the home setting.

Observation characteristics (Leverton et al., 2019)	Applied to our study design
Terminology	Participant observation
Structure	Guided observation
Data collection	Naturalistic (in person without researcher intervention) + ethno-interview technique
Number of researchers; researcher role	3 'researcher-observers', each observing care provided by 2 homecare agencies; conversational only (no participation in care tasks)
Rapport building	1–2 familiarisation visits (contextual notes only)
Time spent observing	Pre-decided: 1–2 familiarisation visits + up to 5 observation visits; duration per observation determined by client's visit time (capped at 2 hours to prevent researcher fatigue and observation saturation)
Recording data	Fieldnote 'jottings' using pen and paper during visit, full notes typed up no more than 48-hours later where possible (to prevent limitations of memory); reflective stance recorded alongside fieldnotes and in reflective journal
Validation and triangulation	Data triangulated with interviews, weekly team discussions, fieldnotes read by wider research team and double-coded during analysis, 'fair dealing' (Mays & Pope, 2000)
Ethical considerations	Researcher-observers assessed capacity of clients with dementia at the start of observations and at each visit; regularly informing clients of purpose for visit

a family member) provided written consent if the person living with dementia lacked capacity. We obtained written consent from family members, healthcare professionals and other homecare workers who were present during observation visits to include their interactions in fieldnotes. We purposively recruited homecare worker and client dyads to include diverse visit types (i.e. personal care and respite visits), schedules and durations.

Data collection

The data collection process is displayed in Figure 1.

Qualitative interviews. We conducted interviews at locations convenient for participants and interviewed people living with dementia and family carer dyads together if preferred. Participants were offered a £20 voucher for their time. Interviews lasted around 1 hour, were audio-recorded and followed a semi-structured topic guide (Supplementary Material). Questions focused on what a training and support programme for homecare workers supporting clients living with dementia should comprise and how it should be delivered. We ceased interviews when data saturation was reached, gathering data until the point of 'diminishing returns, when nothing new is being added' (Bowen, 2008). This was decided upon by reflecting on and reading earlier interview transcripts and meeting with data-collecting co-authors to iteratively discuss preliminary patterns and codes.

Participant observations. Three non-clinical researcher-observers from psychology and sociology backgrounds travelled with and observed homecare workers with clients living with dementia.
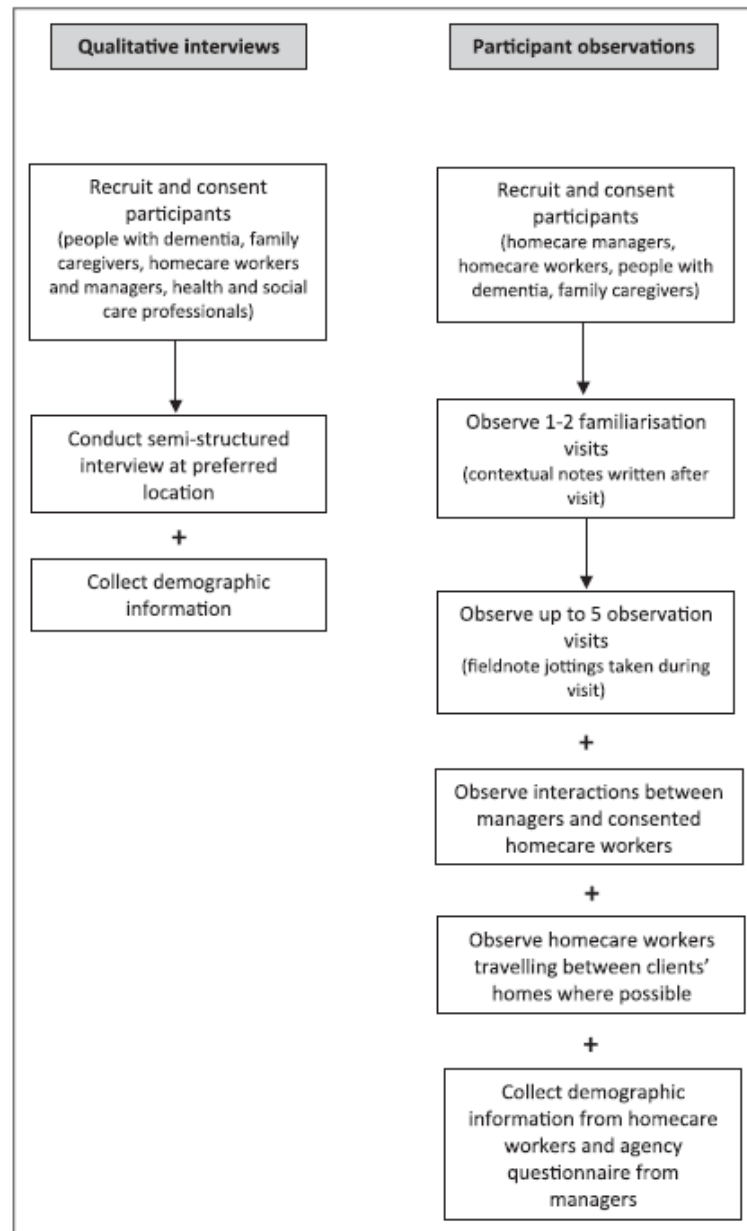
Figure 1. Mapping the data collection process.

Observations included homecare workers providing care, including personal care, and interpersonal interactions during home visits and in agency offices. For each client, we conducted up to two familiarisation visits, during which researcher-observers did not take fieldnotes, aiming to foster familiarity and build rapport (MacLaren et al., 2017); they made contextual notes after the visit. Up to five further observation visits were made during which researcher-observers took 'jottings' (brief fieldnotes) (Emerson et al., 2011).

A semi-structured observation guide (Supplementary Material) focused the observations, aided consistency between researcher-observers and prompted reflexivity; researcher-observers kept reflective journals alongside fieldnotes. The description by Adler and Adler (1987) of a 'peripheral' observer aligns well with the observer stance adopted: we gained first-hand insider perspectives without functionally participating in the homecare. Researcher-observers interacted conversationally as felt natural and used an ethno-interviewing technique (unstructured naturalistic conversation) to enrich fieldnotes (DeWalt & DeWalt, 2011).

Researcher-observers viewed personal care only with consent from the person living with dementia or their nominated consultee (under England and Wales' Mental Capacity Act 2005) and checked for signs of distress from the person living with dementia.

Data analysis

We conducted a reflexive thematic analysis (Braun & Clarke, 2006, 2020), triangulating interview and observation data. Both data sources were transcribed verbatim, and identifiable information was removed. ML read all data for familiarity. ML and co-authors inductively open and double-coded 25% of the interview transcripts across participant groups and 15% of the observation fieldnotes. Similar to the 'Following a thread' approach (Moran-Ellis et al., 2006), we explored how codes from one dataset followed into the other until we developed one interwoven coding framework. We then applied this framework to the remaining interview transcripts and half of the observation fieldnotes until no new codes were found (i.e. thematic saturation). The remaining fieldnotes were read in detail and compared against the framework to ensure verification, comprehension and completeness of the data (Morse et al., 2002). We refined and defined themes and explored divergences between interview and observation data.

We used anonymised identifiers for interview participants and pseudonyms when presenting supporting fieldnotes: 'A' names for homecare workers, 'B' for clients with dementia and 'C' for family carers.

Findings

Sample characteristics

We interviewed 82 participants: 11 people living with dementia, 22 family carers (including 3 dyads, for whom family carers were interviewed separately, though for 2 dyads, the family carer was present when the person living with dementia was interviewed), 19 health and social care professionals and 30 homecare staff (7 managers, 4 office staff and 19 homecare workers) (Table 1).

We observed homecare provided by six commercial agencies (Table 2) with 16 homecare workers (Table 3) and 17 people living with dementia (Table 4). Four homecare workers took part in both the qualitative interviews and participant observations. Twenty homecare workers consented to be observed. Three dropped out prior to familiarisation visits (due to illness, client declining participation and overlap in the researcher-observer's schedule, respectively). One homecare worker

Table 1. Demographic information of interview participants (*n* = 82).

Characteristics	Category	Homecare managers and support staff, n (%) or mean (SD)	Homecare workers, n (%) or mean (SD)	People with dementia, n (%) or mean (SD)	Family carers, n (%) or mean (SD)	Health and social care professionals, n (%) or mean (SD)
N		11	19	11	22	19
Age		47.3 (9.5)	48.9 (12.9)	78.6 (7.8)	57.7 (14.3)	41.4 (10.9)
Gender	Female	9 (81.8)	16 (84.2)	5 (45.5)	12 (54.5)	13 (68.4)
	Male	2 (18.2)	3 (15.8)	6 (54.5)	10 (45.5)	6 (31.6)
Ethnicity	White – British	7 (63.6)	15 (78.9)	8 (72.2)	9 (40.9)	9 (47.4)
	White – Irish	1 (9.0)	0 (0.0)	1 (9.1)	0 (0.0)	1 (5.3)
	White – other	0 (0.0)	1 (5.3)	0 (0.0)	0 (0.0)	4 (21.1)
	Asian – Indian	0 (0.0)	0 (0.0)	0 (0.0)	6 (27.3)	2 (10.5)
	Asian – Bangladeshi	0 (0.0)	0 (0.0)	0 (0.0)	4 (18.2)	0 (0.0)
	Black/Black British – African	2 (18.2)	1 (5.3)	0 (0.0)	0 (0.0)	0 (0.0)
	Black/Black British – Caribbean	1 (9.0)	1 (5.3)	0 (0.0)	0 (0.0)	0 (0.0)
	Other	0 (0.0)	1 (5.3)	2 (18.2)	3 (13.6)	3 (15.8)

did not participate following one familiarisation visit, due to illness. Two people living with dementia from one agency consented to observations but did not take part (due to overlap with the researcher-observer's schedule and reaching our purposive sampling target within that agency). Two people living with dementia were observed during familiarisation visits only, due to subsequent hospitalisation. We observed 104 homecare visits (including 24 familiarisation visits), recording 100-hours of observations, with additional observations within agencies' offices and during travel.

Qualitative analysis findings

We describe four themes responding to our research aim: (1) 'Navigating the homecare identity and role', (2) 'Developing and utilising relational and emotional skills', (3) 'Managing when clients resist care' and (4) 'Drawing on agency and team support'. All themes drew on both methods of data collection. While we did not have an a priori intention to give greater weight to either data source, the balance between them varied by the stakeholder group. Interviews were the primary source of data for non-frontline professionals (e.g. homecare managers) who were not usually present in observations and for family carers. Perspectives of clients living with dementia were gleaned mostly from observations, which allowed perspectives to be conveyed in-the-moment, circumventing memory loss. Health and social care professionals' perspectives featured in both. Observations also allowed us to observe interactions occurring between participants. Interviews and observations seemed to contribute equally to our findings regarding homecare worker perspectives. All participant groups identified challenges of homecare for people living with dementia and plausible solutions to embed into homecare workers' training and support. Some solutions were beyond

Table 2. Characteristics of homecare agencies participating in observations ($n = 6$).

Homecare agency	Location	CQC rating	Total number of clients (% of caseload with dementia or memory problem)	Homecare workers on zero-hour contract (% of all employed)	Care funding	Homecare workers observed	Clients with dementia observed
1	London	Good	91 (39.5%)	85 (100.0%)	Private only	1	1
2	London	Good	28 (53.6%)	1 (6.6%)	Private only	2	2
3	South England	Good	150 (4.6%)	90 (100.0%)	Local authority only	3	2
4	South England	Requires improvement[a]	180 (45.0%)	67 (95.7%)	Private and local authority	5	7
5	North England	Outstanding	112 (62.5%)	74 (93.7%)	Private and local authority	3	3
6	North England	Good	196 (31.6%)	120 (95.2%)	Private and local authority	2	2

Note: CQC: Care Quality Commission.
[a]CQC rating changed from 'Good' to 'Requires Improvement' at the start of the observation period.

Table 3. Characteristics of homecare workers observed providing homecare (*n* = 16).

Characteristics	Category	N (%) or mean (SD)
Age[a]		49 (5)
Ethnicity	White – British	12 (75)
	White – other	1 (6)
	Black/Black British – Caribbean	1 (6)
	Black/Black British – African	2 (13)
Contract type	Employed on zero-hour contract	5 (31)
Employment	Working part-time	5 (31)
	Working full-time	11 (69)
Years worked in care	6 months–1 year	3 (19)
	1–3 years	4 (25)
	3–5 years	1 (6)
	5–10 years	4 (25)
	10 years or more	4 (25)
Years worked in current agency[b]	Less than 6 months	1 (6)
	6 months–1 year	3 (18)
	1–3 years	7 (44)
	3–5 years	2 (13)
	5–10 years	2 (13)
Method of travel	Walk only	1 (6)
	Cycle	1 (6)
	Car	10 (62)
	Bus/bus with a walk	4 (25)
Personal experience of dementia	Yes	6 (38)
	No	10 (62)

[a]Three homecare workers chose not to disclose this.
[b]One homecare worker was unable to specify.

the scope of training, requiring organisational changes, for example, to funding or scheduling arrangements.

Navigating the homecare identity and role

Across stakeholders, there was ambiguity around the role of homecare workers, including boundaries and limits. We outline the different role identities held by homecare workers (subtheme 1) and the subsequent expectations and tensions that arose amongst stakeholders (subtheme 2).

Subtheme 1: Role identity

Homecare workers often adopted parallel role identities, including a proxy-healthcare professional, friend to clients and their family members or the home-help. Holding and sometimes moving between identities could pose challenges.

Proxy-healthcare professional. The homecare role was described as needing the skills traditionally associated with health and social care professional roles: of counsellor, nurse or warden responsible for clients' safety and well-being. We observed situations where homecare overlapped with

Table 4. Characteristics of people living with dementia observed receiving homecare (*n* = 17).

Pseudonym	Age	Sex	Living situation	Capacity to consent	Care funding	Length of each visit
Betty	Missing data	Female	Lives alone	Yes	Private	3 hours
Beverley	77	Female	Lives with spouse	No	Private	1 hour
Bonnie	84	Female	Lives alone	Yes	Private	1.5–3 hours
Belinda	82	Female	Lives alone	No	Local authority	30 minutes
Barbara	80	Female	Lives with son	No	Local authority	30–45 minutes
Brian	61	Male	Lives with spouse	No	Local authority	3 hours (sitting service)
Beth	85	Female	Lives with spouse	No	Local authority	15–30 minutes (4-hour respite visits twice weekly)
Beatrice	96	Female	Lives alone	No	Local authority	3-hour shifts within 24-hour care package
Brenda	93	Female	Lives alone	Yes	Local authority	30 minutes
Benji	84	Male	Lives with spouse	No	Local authority	30 minutes
Bernice	89	Female	Lives alone	Yes	Local authority	15 minutes
Bridgette	94	Female	Lives alone	Yes	Local authority	30 minutes
Boris	77	Male	Lives with spouse	No	Private	2 hours
Bara	98	Female	Lives alone	No	Private	1 hour
Benita	88	Female	Lives alone	No	Private	1–5 hours
Bryony	99	Female	Lives alone	No	Local authority	30 minutes
Bea	89	Female	Lives alone	No	Local authority	30 minutes

healthcare visits, which often involved the healthcare professional positioning the homecare worker as their proxy to carry out tasks in their absence. For example, one homecare worker was instructed by a district nurse to care for a client's wounds. In other examples, homecare workers reiterated healthcare professionals' advice to encourage clients living with dementia to complete necessary tasks:

'Angela reminds Betty that the doctor has told her she must stop using soap to wash her private areas as the soap has been causing her infections. Betty agrees and repeats what she remembers of this correctly, and then drains the sink to remove the soap from the water.' (Agency 1-Observation)

Homecare workers were sometimes uncertain of the extent to which supporting clients with their health care fell within the remit of their role:

'Ashley asks Abbey if they should put in eye drops as Beverly's eye looks sore. Abbey says that they cannot issue medication.' (Agency 3-Observation)

Some healthcare professionals and family carers felt homecare workers lacked sufficient training to carry out health-related tasks. Whereas homecare managers perceived that the value of homecare workers' familiarity and understanding of clients, in addition to their training and experience, should situate them as valued contributors to the healthcare multidisciplinary team, although this was unrecognised and undervalued:

'...Yes, they are not as highly qualified as a district nurse, or an occupational therapist, but they have training, and they are in there seeing the client every day. Whereas nurses might be going in once a week... or when there's a problem. But [their] opinions on things get thrown back quite often.' (Homecare Manager 6-Interview)

Personal companion. Homecare workers were valued by clients and family members as companions, friends or likened to a family member. Homecare workers in turn considered building positive relationships as essential to good care provision and a cherished part of the job, using terms such as 'aunty' or 'good friend' to describe their clients. Discourses around the homecare worker as a companion contrasted with professional discourses, giving rise to a different set of rules, relationships and interactions. They suggested a sense of reciprocity:

'Angela says her and Betty "work like each other's brains".' (Agency 1-Observation)

'Clara describes Alison as an "angel" and a "God-send", saying that she is like a daughter to her and Benji. She tells me that Alison was the first homecare worker that Benji had and Alison had also just started being a homecare worker, so they learned what to do together.' (Agency 4-Observation)

The quote above implies that some skills are not taught but evolve throughout the course of the relationship with the client and their family.

With the identity of personal companion, professional boundaries could blur. In some cases, the sense of being part of the in-group led to homecare workers passing judgements on less involved or distanced family members, or becoming involved in activities beyond the remit of the homecare role:

'And then I went in the next day, [she] looked anxious again and I said, "what are you worrying about?". She said, "I don't want my children here when I write the will". So, I had to ring the daughter and son and tell them that she wants me be there, and I actually witnessed her will.' (Homecare Worker 12-interview)

Home-help. Homecare workers also provided domestic support, substituting for aspects of life the client could no longer do:

'And you do have to do everything, from personal care to medication to gardening to cooking. You really are sort of being the eyes and the ears and the hands of that person.' (Homecare Manager 3-interview)

This identity was most clear cut for homecare workers as domestic tasks were outlined in the clients' care plan. However, challenges arose when balancing these tasks with the relational and social needs of clients and family members.

Subtheme 2: Role expectations

Role ambiguity gave rise to tensions. Homecare workers faced dilemmas when stakeholders had different expectations of their role. One person living with dementia expressed frustration when homecare workers seemed too focused on completing the care plan's set tasks:

> '...give more time for the people, rather than the doing... It then gives the [homecare worker] the time to ask the person how they are, instead of fussing around doing the practical things; they can actually talk to the person then.' (Person living with dementia 17-interview)

Balancing the care plan with the client and their family's wishes and expectations tested homecare workers' professional boundaries when asked to partake in tasks or activities beyond their role's remit, or outside scheduled visit times. In one observation, a family carer asked a homecare worker to monitor the client via a camera, beyond her working hours:

> 'Angela shows me the motion-sensored camera in Betty's bedroom that Cliff had asked her to monitor. The camera is connected to an app on Angela's phone which she often checks to see that Betty is safe when she is alone. Angela says that if she saw anything was wrong, she would be the first to rush over.' (Agency 1-Observation)

Being asked to take on such a position could bring rewards of esteem and satisfaction from being trusted and autonomous, but also anxieties from onerous or intrusive expectations; Angela reported 'not being able to switch off' from her role, with other homecare workers describing a weight of responsibility. Some homecare workers were more cautious of the repercussions of taking on responsibility beyond their role:

> 'I get on well with her [the client's wife], it's just when she wants to have things her own way, and I know that it's not the right way, rather... It's the policies, the procedure that has to be followed... we have to abide by the rules.' (Homecare Worker 13-Interview)

However, homecare workers' competency or value could be questioned if they did not meet stakeholders' expectations; one pertinent example described the homecare role as 'low level' work (Healthcare Professional 18-Interview). Some homecare workers reported asking for advice or support from their manager to navigate such situations without disappointing stakeholders.

Developing and utilising relational and emotional skills

Close and complex relationships often developed between homecare workers and clients living with dementia and their family carers. Homecare workers required key relational and emotional skills to develop (subtheme 1) and manage (subtheme 2) these relationships.

Subtheme 1: Building relationships with clients living with dementia and their family carers

All stakeholders felt that 'getting to know' and becoming familiar with clients and their families were critical to homecare for people living with dementia. The skills required included a need to '*talk the same language*' (Homecare Worker 23-Interview), as well as '*getting to know the person... what*

the person likes or doesn't like, what the person can do, what they can't do' (Family carer 22-Interview).

Valuing and respecting the client as '*a person with dementia. They're not dementia*' (Homecare Worker 12-Interview) was a skill that was imperative to developing positive relationships. Agencies could facilitate positive relationships by matching homecare workers with clients, based on age, similar interests or social and cultural values. In one example, we heard about a family discontinuing their support when the homecare worker's care provision was perceived to not align with the client's culture:

> *'The thing is, because she likes a certain way of cooking, a certain type of food, she didn't want someone, you know, a Caucasian female coming in and making like a vegetable stew with water and some salt, and then here you are Madam. It's not her cup of tea... So, it's very difficult. She basically refused their assistance.' (Family Carer 13-Interview)*

Developing relationships of familiarity often relied on consistent visit scheduling. Regularly seeing new faces was difficult for people living with dementia. Homecare workers also faced challenges when they were scheduled to visit a new client at short notice (i.e. following a hospital admission) or when allocated short visits. Clients living with dementia were understood to need more time, particularly if homecare workers were '*not as skilled as they could have been*' (Healthcare Professional 16-Interview).

Subtheme 2: Managing complex attachments and boundaries

Complex mutual attachments formed, which could be difficult to navigate within the professional boundaries:

> *'I think we get quite attached to her as much as she's got attached to us really... it's like being with your gran. We're not supposed to get emotionally involved, but I think we're all human beings.' (Homecare Worker 18-Interview)*

Both clients and homecare workers had 'favourites'. Indeed, homecare workers described finding it hard to leave certain clients, often staying on in their own unpaid time. There was a sense in many narratives that work and contact with clients outside of contracted hours were virtuous and a sign of doing the job well:

> *'Sometimes, I can be there for the next half an hour, but I don't care, just knowing that I'm doing something good. So, I try to make her as comfortable as possible because she's on her own.' (Homecare Worker 10-Interview)*

We observed situations where homecare workers brought flowers, food and home-baked goods for clients. In one situation, a homecare worker took a client's family carer out for lunch in her own time. Becoming emotionally attached to clients and their family members could give rise to difficult emotions, particularly when clients died:

> *'I have to deal with then, the deaths of clients and it hits my staff really, really hard... I go to funerals of clients and people say sometimes you get hardened to things, but you don't.' (Homecare Manager 7-Interview)*

In one case, a homecare worker reported 'dreading' the loss of her favourite client but did not know of any support to help her deal with this.

Managing when clients resist care

A key challenge facing homecare workers in supporting people living with dementia was how to work safely and effectively when clients displayed resistant behaviour. This often occurred during personal care. We observed a situation where a client was frustrated at being told she must stay in bed (a decision made by social workers and family due to deteriorated mobility); the homecare worker appeared unsure how to respond:

> 'Beatrice remains very distressed and shouts to be left alone. Audrey appears deflated but offers Beatrice a drink again; she pushes the cup away. Audrey comes over to me to apologise, saying "it isn't very nice when Beatrice is like this". Beatrice's distress has been ongoing for 25-minutes and she remains asking to go to the toilet. Audrey has stopped responding.' (Agency 4-Observation)

With the same client, Audrey was observed to be *'physically keeping Beatrice on the bed with her own body'*, to prevent Beatrice from falling out of the bed as her frustration increased. Homecare workers and managers described training and support as important to equip homecare workers with the skills to manage such challenges, including where clients were verbally or physically aggressive:

> '... [for someone] to be at the end of the phone, to say "look, I need somebody else here, this is getting a bit out of hand". Then the support would have to be there, wouldn't it? You can't just put somebody in a situation with no armour, as such... You've been thrown to the wolves, haven't you? You've got no training, how are you supposed to deal with somebody, with an illness that you know nothing about?' (Homecare Worker 19-Interview)

Understanding resistant behaviour as communication was described as important by all stakeholders; this was facilitated via familiarity and empathy:

> 'They might have toothache... When they start lashing out and becoming... Oh people say "well they're a difficult person". No, it's probably because they've been in pain for a long time and besides, they're also out of their mind from the pain and they're tired from it, and they get angry.' (Family carer 22-Interview)

Experiential learning could enable homecare workers to develop these valuable skills. One homecare worker discussed encouraging others to try being moved in a hoist during training, to experience what it felt like. Ethical considerations also emerged when faced with client's refusal; homecare workers required skill and knowledge to navigate between clients' capacity and best interests.

Drawing on agency and team support

Homecare agencies and therefore managers were crucial in providing emotional (subtheme 1) and practical (subtheme 2) support to homecare workers.

Subtheme 1: Emotional needs

Homecare workers often worked in isolation, with limited regular contact with other workers or the agency. They described feeling a lack of emotional support when challenges arose:

> '*I think it would be nice to have somebody... that if it got too much like it was with [Client], that they could understand how I felt that day... And afterwards, I cried all the way home....*' *(Homecare Worker 19-Interview)*

In contrast, some homecare workers were scheduled to work together with clients. One homecare worker who worked as a team providing a 24-hour care package reported feeling '*lucky to have a good team around*', describing her relationship with the other care workers as '*a close unit*' and '*supportive*' *(Homecare Worker 18-Interview)*.

Some homecare workers sought informal peer support during joint shifts. This was often their only opportunity for peer support but could lead to homecare workers chatting or venting frustrations in front of clients. In some observation visits, homecare workers would vent to the researcher-observers:

> '*Alina and Ashley talk to each other while they work and laugh together. Belinda gets distressed again by this and shouts. Alina says again that they are not laughing at her and says sorry.*' *(Agency 3-Observation)*

All participant groups acknowledged the often challenging nature of the role and the importance of support from managers. Supportive approaches included managers adopting an open-door policy and office staff being always contactable, particularly when visits occurred outside of business hours.

Subtheme 2: Practical support

Poorly organised visit scheduling caused frustration for all participant groups. Short-staffing and visit-cramming led to homecare workers having little time for breaks, training or self-care:

> '*We did a Care Certificate and I'm pretty sure we did some dementia training... Sorry, I'm yet to do it.... I was working when it was on.*' *(Homecare Worker 26-Interview)*

Agencies faced difficulties when homecare workers called in sick at short notice. We observed office staff continuously phoning or texting homecare workers to find cover, often disrupting and distressing care workers and their clients during visits:

> '*While Amy is washing Beth, the phone in her back-pocket rings and she answers the call. It is the agency asking her to cover a shift. Amy continues to wash Beth's private areas as she speaks on the phone. Amy moves towels over Beth's body to keep her warm. Beth is silent.*' *(Agency 4-Observation)*

Homecare workers often felt pressured to take on extra work, sometimes working long days without breaks. Busy schedules affected reliability and punctuality causing frustration for people living with dementia and their family carers:

'I know how difficult it is for [homecare workers] to stick to a sensible timetable. But, I don't want to be greeting visitors unless I'm half dead at 11 at night, when they should have been there at 10 in the morning.' (Person living with dementia 16-Interview)

Homecare workers were sometimes visibly tired. We observed a homecare worker fall asleep during a 'sitting service' (a longer duration respite visit) and another who badly cut herself while washing-up dishes.

Discussion

All stakeholders acknowledged the importance of skills to get to know and understand their clients living with dementia, to acknowledge their social and cultural values, to treat them with respect and to provide flexible, person-centred care. We found that greater role clarity and understanding of how to manage key relationships within the professional boundaries were important aspects of training for homecare workers. We described how homecare workers adopted a range of role identities, often in parallel, which brought conflicting expectations that could require skilful and at times, challenging negotiations.

Boundaries sometimes blurred between developing professional relationships and getting excessively emotionally involved, with a sense that it was up to individual homecare workers to navigate often close and complex relationships with clients and their families. Our findings echoed those of Schneider et al. (2019), who found that 'going the extra mile was deployed in the organisation to indicate the standard of dedication that was expected of care workers'. We found that homecare workers faced difficulties in providing safe and effective support with clients who displayed resistant behaviours particularly during personal care. Perhaps the most powerful language we heard to signify the importance of training and support was of feeling 'thrown to the wolves' without sufficient training. While homecare was sometimes perceived as teamwork, it was more often isolating and overwhelming, with a lack of opportunity for peer or managerial support, even after the death of a client.

Valuing flexible, responsive, person-centred care

The UK Home Care Association called for 'greater flexibility for homecare providers to innovate and shape care with the individual' (UKHCA, 2015). Adopting a more flexible way of working may involve homecare workers drawing upon their understanding of, and familiarity with their clients living with dementia, in order to provide responsive, person-centred care, tailored around the individual and their needs. Considering how to do this within everyday constraints may be an important dimension for training, with homecare workers have opportunities to reflect as a team on dilemmas and tensions, while exploring potential solutions.

Our findings regarding the diversity and ambiguity of the homecare worker role reflect those across other care staff (D'Astous et al., 2017; Vassos et al., 2013); this may suggest a desire for a more flexible working style and care approach. The growing popularity of directly employed care workers (i.e. Personal Assistants) in England reflects this desire among clients, families and homecare workers. These workers value the variety of their work and opportunities to adjust to the client's needs and their relationships (Woolham et al., 2019), beyond the constraints of a care plan.

Relationship-focused care

We found that a relationship-focused care approach was central to homecare for people living with dementia. Getting to know clients' physical, emotional, social and cultural needs was identified as pivotal in developing these relationships. The different role identities that homecare workers adopted in practice may influence the relationships they form with clients, family carers and other care professionals. Social and communication skills can be developed through training; however, there are key organisational practices beyond training, that may be necessary to harness homecare relationships. We identified consistent visit scheduling and a process of matching homecare workers and clients as potentially helpful practices. Where a matching process is not possible within existing practice, training can develop homecare workers' empathy and 'emotional intelligence' (Schneider et al., 2019). Relationship-focused care approaches (Nolan et al., 2004; Schneider et al., 2019) can be drawn upon to equip homecare workers with the skills to value reciprocity, mutuality and empathy, while supporting homecare workers to securely navigate and manage these relationships within the professional boundaries of the role.

We identified the presence of often complex family dynamics as important to acknowledge in training (see also Manthorpe et al., (2020)). Where homecare workers valued opportunities for peer support and team-based learning, this indicates that training in small groups to discuss and reflect on real-life examples may be effective for problem-solving. Using real-life examples and problem-solving can be helpful in acknowledging the complexities of homecare work (Surr et al., 2017).

Supporting homecare workers

We heard about and observed the emotional and practical challenges faced by homecare workers when providing care to clients living with dementia. Facilitating opportunities for peer support and managers adopting an 'open-door', accessible communication approach were seen as ways to support homecare workers' emotional needs, while incorporating breaks and avoiding visit-cramming could support their practical needs. Homecare workers reported experiencing grief (as well as anticipatory grief) when clients died. Training can help to prepare homecare workers for the loss of clients and dealing with the difficult emotions that were sometimes associated with the role. Beyond training, homecare agencies can support staff by making practical arrangements, for example, by enabling staff to attend clients' funerals (Yeh et al., 2018).

Our findings regarding the effects of emotional labour on care staff are not new (D'Astous et al., 2017; Franzosa et al., 2019; Schneider et al., 2019); however, role ambiguity, unrealistic expectations and care provision in the intimate setting of the home may exacerbate this. Working in clients' homes, as opposed to hospital or residential settings, may neutralise power dynamics and allow for greater autonomy and opportunities for informal care and relationship development (Bolton & Wibberley, 2014); there may be scope within training to consider and reflect on the impact of providing care in clients' homes. The home as a site of care is complex and warrants further attention (Leverton et al., 2021).

Practice implications

Drawing upon a rights-based approach, policy strategies emphasise a drive towards improving quality of life and quality of care for people living with dementia (Cahill, 2020). Our findings add to a growing evidence-base around dementia-specific training and support in achieving good quality dementia care, in addition to good working conditions and recognition for homecare workers.

Our findings build on previous work (e.g. the BOUGH study by Schneider et al. (2019)) indicating that the relational aspects of homecare for people living with dementia (including the relational complexities between stakeholders) are an important dimension of dementia-specific training and support. A reflective, team-based system of training may be effective in facilitating a more flexible and responsive way of working, within a protective and supportive professional framework. Unrealistic role expectations can have a detrimental impact on care provision and homecare worker well-being (D'Astous et al., 2017); thus, homecare agencies may also benefit from developing a clear message from the start of the service, outlining its scope so to set and manage expectations for clients living with dementia and family carers.

We found that homecare workers faced ethical dilemmas when providing care to clients living with dementia who displayed resistant behaviours (i.e. during personal care). Developing a clear understanding of how to provide care that is in the client's best interests while also respecting their wishes is a key area for training. Experiential learning may help to develop necessary skills to deliver safe and effective care, with empathy, dignity and respect (Kiosses et al., 2016).

Training and support interventions cannot be considered in isolation from the wider context of social care. Organisational practice-level changes may be necessary to fully implement change into practice; a collaborative, whole systems approach can help to achieve this (McPherson, 2020; McPherson & Abell, 2020). For example, continuity of care and consistent scheduling facilitate relationship development that is valued by all stakeholders, but they require sufficient funding, staffing stability and capacity. Care workers on zero-hour contracts experience employment instability and poor mental health (Ravalier et al., 2019; Skills for Care, 2018); training and support alone cannot compensate for financial instability. Beyond this, constraints in this sector are not uniform. Typically, privately funded clients receive longer care visits, and local authority funders may be less able to pay homecare workers to attend training (Atkinson et al., 2018).

The UK Home Care Association's (UKHCA, 2015) call for more consistent training for the homecare workforce includes advanced accredited training qualifications to allow specialisation, such as dementia care. There is an argument to professionalise the social care workforce to tackle its endemic problems (Dromey & Hochlaf, 2018). Regulated working policies would improve quality of care for clients and greater working conditions, recognition and value for staff (Scales et al., 2017). Yet professionalisation of the sector is debated, with fears that pressure of registering and attaining qualifications will drive staff away from an already short-staffed workforce (Hayes et al., 2019).

While we conducted this study before the COVID-19 pandemic, it has shone light on the importance and necessity of homecare, particularly for people living with dementia and their family carers (Giebel et al., 2020). Our finding that homecare workers often felt they had little support, even when faced with the death of a client, is heightened in the current circumstances. As some envision a kinder post-pandemic society which values essential workers, our study is a timely reminder of how far we may be from a homecare workforce that feels sufficiently valued, supported and trained.

Strengths and limitations

This is, to our knowledge, the largest ethnographic study to consider the skills, training and support needs of homecare workers who provide care to people living with dementia, from the perspectives of key stakeholders.

Rapid ethnographies have been criticised for jeopardising the richness of data (Pink & Morgan, 2013), though they are considered well-suited to the more immediate priorities and concerns of applied health and care services (Burgess-Allen & Owen-Smith, 2010; Vindrola-Padros & Vindrola-Padros,

2018). The quality of our study was enhanced through data triangulation, documentation of the researcher-observers' reflective stance and use of 'fair dealing' to represent a range of perspectives (Mays & Pope, 2000).

Conclusion

The value of homecare for people living with dementia necessitates a workforce equipped with high-quality dementia-specific training and support, that acknowledges the key relational aspects of the homecare role. Where a flexible, responsive, person-centred service is required, training can enable homecare workers to feel secure and supported in doing so within a professional framework. The well-being of homecare workers can be reinforced through ongoing practical and emotional support from agency managers and peers. Corresponding organisational practices are needed, taking into account the wider context of the care sector where poignant challenges such as low pay and poor staff retention exist.

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Supplemental Material

Supplemental material for this article is available online.

Appendix 19   Published independence paper

This paper was published in *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Geriatric Epidemiology and Mental Health* (Leverton et al., 2021a).

ORIGINAL PAPER

Supporting independence at home for people living with dementia: a qualitative ethnographic study of homecare

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Abstract

Purpose The aim of this ethnographic study was to investigate how homecare workers support or inhibit independence in people living with dementia.

Methods We undertook 100 h of participant observations with homecare workers ($n = 16$) supporting people living with dementia ($n = 17$); and 82 qualitative interviews with people living with dementia ($n = 11$), family carers ($n = 22$), homecare managers and support staff ($n = 11$), homecare workers ($n = 19$) and health and social care professionals ($n = 19$). We triangulated data and analysed findings thematically.

Results We developed three themes: (1) independence and the home environment, highlighting ongoing negotiations between familiarity, suitability and safety for care; (2) independence and identity, exploring how homecare workers' understanding of their clients' identity can enable active participation in tasks and meaningful choices; and (3) independence and empowerment, considering the important position of homecare workers to advocate for clients living with dementia while navigating authoritative power amongst proxy decision-makers.

Conclusion We consider that person-centred care should also be home-centred, respecting the client's home as an extension of self. Homecare workers can use their understanding of clients' identities, alongside skills in providing choice and developing relationships of interdependence to engage clients in everyday tasks. Homecare workers are well placed to advocate for their client's voice within the care network, although their ability to do so is limited by their position within power structures.

Keywords Dementia · Homecare · Domiciliary care · Independence · Qualitative research · Ethnography

Introduction

Independence, considered central to active ageing, is defined by the World Health Organisation [1] as the ability to function in daily life with no or little help from others. Globally, dementia affects over 46 million people and is a leading cause of disability [2]. Living at home for as long as possible is an important manifestation of independence [3], although independence for people living with dementia may be more usefully conceptualised as the ability to manage life with 'some degree of independence' [4, 5]. Recent models of living independently with dementia acknowledge a tension between independence as an expression of full autonomy and the interdependence that can enable people with dementia to live longer at home [6]. Two-thirds of people diagnosed with dementia in the UK live in their own homes [7] often supported by family, friends, neighbours and care services.

Sixty percent of the UK homecare workforce work with people living with dementia [8] providing personal, basic nursing care and domestic support. Most homecare agencies explicitly adopt person-centred care values, which can be challenged by the task-orientated nature of care planning and delivery in an under-resourced sector. Person-centred

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dementia care considers individuals within their social context [9] and focuses on valuing the individual, promoting independence and functional abilities [10].

Few studies have included people living with dementia in research about their care. In one such study, people living with dementia prioritised independence (including opportunities for meaningful activities), self-management of dementia symptoms and quality of life [11]. In contrast, family members, who are often substituted as a proxy, prioritise their relative's safety [12, 13]. We used ethnographic observations and qualitative interviews to answer our exploratory research question: how can homecare workers' support or inhibit independence in their clients living with dementia? We sought to capture a wide range of stakeholder perspectives, from people living with dementia at varying stages of the condition, family carers, health and social care professionals (including general practitioners, social workers, and commissioners) and homecare staff. This work informed the development of the NIDUS-Professional training and support programme to enhance homecare workers' understanding and implementation of person-centred dementia care [14].

Methods

Study design

This qualitative study was nested within the 'New Interventions for Independence in Dementia Study' (NIDUS) [ISRCTN15757555].

Ethical considerations

London (Camden and King's Cross) National Research Ethics Committee approved the study (reference: 17/LO/1713) in November 2017. We interviewed participants with capacity to consent, and people living with dementia without capacity to take part in research were included in participant observations, following the Mental Capacity Act (England & Wales) 2005 provisions to identify personal consultees who provided written consent. We obtained written informed consent from all participants with capacity to consent.

Sampling and recruitment

For the qualitative interviews, we purposively recruited people diagnosed with dementia and family carers from three geographically diverse National Health Service (NHS) memory services, commercial homecare agencies, an Alzheimer's Society Experts by Experience

group and Twitter. Health and social care professionals were recruited via UCL, NHS memory services and local authorities. We recruited homecare managers, support staff and homecare workers from urban and semi-rural/rural homecare agencies. Purposive sampling ensured participant diversity in age, ethnicity, role (health and social care professionals and homecare staff), relationship to the person with dementia (family carers), homecare service experience (people living with dementia) and shift-pattern and client-type (homecare workers).

For the participant observations, we included homecare agencies whose staff had participated in our qualitative interviews and recruited additional agencies to observe care provision with both private and/or local authority funded clients from agencies across urban and semi-rural locations. Homecare workers planning to leave the agency within the next 6 months were excluded to ensure we could complete data collection.

Data collection

We undertook: 1) semi-structured qualitative interviews (March 2018–September 2018); and 2) participant observations (August 2018–March 2019).

Qualitative interviews took place in locations convenient for participants. People living with dementia and family carer dyads were interviewed together if preferred. Interviews were guided by a semi-structured topic guide (Appendix A) and lasted around 1 hour; they were audio-recorded and transcribed verbatim. Participants were offered a £20 voucher for their time. Recruitment ceased when saturation was reached [15].

The participant observations were guided by our earlier methodological review of observational studies of homecare [16]. Three researcher-observers (ML, AB and JBD) from psychology and sociology backgrounds conducted naturalistic observations of homecare workers, guided by a semi-structured observation guide (Appendix B) intended to enhance consistency of fieldnotes across observers and prompt reflexivity. Researcher-observers aimed to minimise impact on homecare visits but did engage conversationally with participants, using an ethno-interview technique to enrich fieldnotes [17]. After one or two familiarisation visits to build rapport, we observed up to five further visits, taking brief fieldnote 'jottings' which were completed after the visit [18]. Observations included short (i.e. 15-min personal care visit) and long visits (i.e. 3-h respite or 'sitting service'), funded privately or by local authorities. Observations were capped at 2 hours to prevent participant burden and researcher fatigue. The researcher-observers met weekly to discuss

their observations and reflective notes. The data collection process is detailed further in Appendix C.

Data analysis

We adopted a critical realist lens [19] and thematically analysed transcribed interviews and observational data [20, 21], triangulating findings between sources. We used NVivo12 software to organise the data and performed an initial inductive analysis of each dataset. ML and two members of the research team independently coded 25% of the interviews across all participant groups to develop an initial coding framework. ML and other research team members coded 15% of observation fieldnotes from which ML developed a second coding framework. We drew on the 'Following a thread' methodology [22] to iteratively integrate the findings, exploring how codes from one dataset followed into the other, and vice versa, developing one interwoven framework. We then applied the framework to the remaining interviews and half of the observation fieldnotes, adding new codes to the framework until no new codes were found. The remaining fieldnotes were read in detail and compared against the framework to ensure verification, comprehension and completeness of the data [23]. Themes were refined and defined following discussions within the team. We also looked for divergences between the two datasets.

Results

Study participants

We interviewed 82 participants: 11 people living with dementia (PLwD), 22 family carers (FC), 11 homecare managers and support staff (HMSS), 19 homecare workers (HCW) and 19 health and social care professionals (HSCP). Health and social care professionals included Medical General or Assistant Practitioners, Psychologists, Social/Support workers, Local Authority Commissioners (funders), amongst other roles. We conducted 100-h of participant observations with 16 homecare workers and 17 clients living with dementia, across 6 homecare agencies. Where possible, we travelled with homecare workers between clients' homes and observed them interacting with agency staff. Tables 1, 2, 3 for participant demographic information and (Table 4) for homecare agency information.

Qualitative analysis

Interview participants are anonymously identified by abbreviations as above and ID number, while observation participants are pseudonymised: 'A' names for homecare workers, 'B' names for people with dementia and 'C' names for family carers.

We developed three themes capturing how homecare workers support or inhibit independence in clients living with dementia:

Theme 1—Independence and the home environment

All participant groups interviewed described *"being in their own home in their own surroundings"* (HCW19-interview) and the ability to *"move freely around their home, to do whatever it is they want to do"* (HCW17-interview) as key to maintaining independence. Our two subthemes explore how the home environment enabled independence through familiarity but could also compromise (1) the delivery of the care; and (2) client safety, requiring a balancing of risk and autonomy.

Table 1 Details of qualitative interview participants (homecare workers are presented in Table 2)

Characteristics	Category	Homecare managers & support staff $n=11$ n (%) or mean (SD)	People living with dementia $n=11$ n (%) or mean (SD)	Family carers $n=22$ n (%) or mean (SD)	Health & social care professionals $n=19$ n (%) or mean (SD)
Age		47.3 (9.5)	78.6 (7.8)	57.7 (14.3)	41.4 (10.9)
Gender	Female	9 (81.8)	5 (45.5)	12 (54.5)	13 (68.4)
	Male	2 (18.2)	6 (54.5)	10 (45.5)	6 (31.6)
Ethnicity	White–British	7 (63.6)	8 (72.2)	9 (40.9)	9 (47.4)
	White–Irish	1 (9.0)	1 (9.1)	0 (0.0)	1 (5.3)
	White–Other	0 (0.0)	0 (0.0)	0 (0.0)	4 (21.1)
	Asian–Indian	0 (0.0)	0 (0.0)	6 (27.3)	2 (10.5)
	Asian–Bangladeshi	0 (0.0)	0 (0.0)	4 (18.2)	0 (0.0)
	Black/Black British–African	2 (18.2)	0 (0.0)	0 (0.0)	0 (0.0)
	Black/Black British–Caribbean	1 (9.0)	0 (0.0)	0 (0.0)	0 (0.0)
	Other	0 (0.0)	2 (18.2)	3 (13.6)	3 (15.8)

Table 2 Self-reported demographic information of homecare worker participants across the two methods of data collection: qualitative interviews and participant observations

	Homecare workers[a]: interview n=19	Homecare workers: observation n=16
	n (%) or mean (SD)	n (%) or mean (SD)
Age	48.9 (12.9)	49.0 (5)
Gender		
Female	16 (84.2)	16 (100)
Male	3 (15.8)	0 (0)
Ethnicity		
White British	15 (78.9)	12 (75)
White Other	1 (5.3)	1 (6)
Black/Black British Caribbean	1 (5.3)	1 (6)
Black/Black British African	1 (5.3)	2 (13)
Other	1 (5.3)	0 (0)
Contract type		
Employed on zero hours contract	3 (15.8)	5 (31)
Employment		
Working part time	8 (42.1)	5 (31)
Working full time	9 (47.4)	11 (69)
Other (e.g. varied shift patterns)	2 (10.5)	0 (0)
Years worked in social care		
6 months–1 year	3 (15.8)	3 (19)
1–3 years	2 (10.5)	4 (25)
3–5 years	4 (21.1)	1 (6)
5–10 years	5 (26.3)	4 (25)
More than 10 years	5 (26.3)	4 (25)
Years worked in current agency[a]		
Less than 6 months	2 (10.5)	1 (6)
6 months–1 year	4 (21.1)	3 (18)
1–3 years	5 (26.3)	7 (44)
3–5 years	3 (15.8)	2 (13)
5–10 years	3 (15.8)	2 (13)
More than 10 years	1 (5.3)	
Personal experience of dementia in family/friend		
Yes	9 (47.4)	6 (38)
No	10 (52.6)	10 (62)

[a]One homecare worker (interview only) was unable to specify length of time worked in current homecare agency

Subtheme 1: Familiarity versus adaptation Delivering care in homes not designed as care environments often resulted in imperfect solutions which were necessary to enable essential care, but could inhibit clients' access to parts of their home, and the independence the care sought to enable, as well as to homecare workers' safety and well-being:

'*Audrey tells me that they are unable to fit the wheelchair through the door frames so Beatrice mainly spends her time between the TV room and her bedroom next door.*' (Fieldnote).

'*Amy manoeuvres the hoist as Ava holds Beth's legs still. Amy struggles to swiftly manoeuvre the hoist on the carpeted floor having to put physical effort into pushing it. Amy bumps into a table as she does this which jolts Beth.*' (Fieldnote).

As clients' homes often required adaptations to support independent living, the environment shifted from a personal space to one with visible signs of disability and care: disposable gloves, bathroom adaptations, living rooms converted into bedrooms, agency files and notes, and homecare workers' possessions:

Table 3 Characteristics of clients living with dementia observed receiving homecare (n=17)

Pseudonym	Age	Sex	Ethnicity	Living situation	Capacity to consent	Care funding	Scheduled visit duration	Requires support with
Betty	Missing data	Female	White British	Lives alone	Yes	Private	3 h	Medication management, meal preparation, prompt washing and support with dressing, domestic support, arranging and accessing appointments in the community and food shopping
Beverley	77	Female	White British	Lives with spouse	No	Private	1 h	All support delivered in bed: personal care, dressing, companionship and domestic support
Bonnie	84	Female	White British	Lives alone	Yes	Private	1.5–3 h	Personal care, meal preparation, medication management, domestic support and accessing the community
Belinda	82	Female	Black Caribbean	Lives alone	No	Local authority	30 min	Meal preparation, meal time companionship and medication management
Barbara	80	Female	White British	Lives with son	No	Local authority	30–45 min	Getting out of bed, personal care, meal preparation, companionship during mealtime and medication management
Brian	61	Male	White British	Lives with spouse	No	Local authority	3 h (sitting service)	Respite for family carer, meal preparation and personal care
Beth	85	Female	White British	Lives with spouse	No	Local authority	15–30 min+4 h respite visits twice weekly	All support delivered in bed: personal care, reposition and assess pressure areas, transfer using hoist and respite for family carer
Beatrice	96	Female	White British	Lives alone	No	Local authority	3 h shifts within 24 h care package	All personal care needs require support
Brenda	93	Female	White British	Lives alone	Yes	Local authority	30 min	Meal preparation
Benji	84	Male	White British	Lives with spouse	No	Local authority	30 min	Personal care, support with dressing and medication management
Bernice	89	Female	White British	Lives alone	Yes	Local authority	15 min	Meal preparation and medication management
Bridgette	94	Female	White British	Lives alone	Yes	Local authority	30 min	Meal preparation, medication management and domestic support
Boris	77	Male	British	Lives with spouse	No	Private	2 h	Personal care, meal preparation, companionship, mental stimulation and mobility support around home
Bara	98	Female	Missing data	Lives alone	No	Private	1 h	Personal care, support with dressing, meal preparation, administering medication and domestic support
Benita	88	Female	British	Lives alone	No	Private	1–5 h	Domestic support, companionship, accessing the community, arranging appointments, food shopping and pet care

Table 3 (continued)

Pseudonym	Age	Sex	Ethnicity	Living situation	Capacity to consent	Care funding	Scheduled visit duration	Requires support with
Bryony	99	Female	White British	Lives alone	No	Local authority	30 min	Personal care, dressing, meal preparation, medication management and domestic support
Bea	89	Female	White British	Lives alone	No	Local authority	30 min	Meal preparation, medication management, domestic support and companionship

'Annie says that the dining table is used to leave messages to those involved in Benita's care–e.g. a folder that bills are put into for the family, notes for other homecare workers, etc. Annie apologises to me that it looks messy.' (Fieldnote).

'There is a bike obstructing the hallway–Audrey tells me that one of the other homecare workers had left her bike in the house while she was on holiday. Beatrice had noticed a few times and asked for it to be taken out of her home.' (Fieldnote).

These changes and adaptations could be depersonalising and overshadow the familiarity of the home. The latter example suggests that Beatrice's home was not always treated as a private space, and her requests for the bike to be removed were unheeded.

These adaptations, however, often enabled people with dementia to continue living in a familiar environment. We observed one client and his wife who had recently moved to a more accessible home with a wet-room equipped with rails. Here, we heard how the loss of familiarity of a known environment was frightening for the person living with dementia:

'Caroline informed me earlier that Brian finds the bathroom claustrophobic and they [FC and HCW] often have trouble getting him in there.' (Fieldnote)

Subtheme 2: Safety and risk

There was often uncertainty about whether the risks of remaining in the familiar, yet sometimes unsuitable environment were justified. One client's house had steep stairs; which the homecare worker herself had reported feeling 'unsteady' on. This exacerbated the homecare worker's concerns on visits where this client was slow to open the door or failed to answer when she arrived:

'The atmosphere felt tense while standing outside Bernice's door as Alison attempted to gain entry. After several times ringing the front door, Alison asked the agency to call Bernice's house phone which she did not answer. Alison sighed and said she didn't think it was fair that Bernice lived on her own.' (Fieldnote).

Bernice also used a chair to barricade her front door overnight, while another client expressed feeling 'vulnerable' while waiting for his wife to return home after the homecare worker had left.

Risks associated with the home environment were a major concern for homecare workers and family carers, but all participants described needing to find a balance between managing risk and supporting independence:

"I think she is entirely fed up with me, I think she sees me as like a jailer really. Which I'm not, I'm only trying to prevent her falling or helping her … It's difficult to judge the line." (FC32-interview).

Table 4 Characteristics of homecare agencies participating in observations ($n = 6$)

Home-care agency	Location	Care Quality Commission (CQC) rating	Total number of clients (% of clients with dementia or memory problem)	Homecare workers on zero hours contract (% of all employed)	Client funding	Dementia-specific training offered	Homecare workers observed	Clients with dementia observed
1	London	Good	91 (39.5)	85 (100.0)	Private	Accredited training, offered quarterly or as needed	1	1
2	London	Good	150 (4.6)	90 (100.0)	Local authority	Non-accredited in-house training, offered at point of induction + yearly	2	2
3	South England	Good	28 (53.6)	1 (6.6)	Private	Non-accredited training at point of induction, some staff offered external advanced dementia training	3	2
4	South England	Good[a]	180 (45.0)	67 (95.7)	Private and local authority	Accredited training, offered yearly	5	7
5	North England	Outstanding	112 (62.5)	74 (93.7)	Private and local authority	Dementia awareness training at point of induction + accredited training offered to some staff	3	3
6	North England	Good	196 (31.6%)	120 (95.2%)	Private and local authority	Accredited in-house training, offered at point of induction + yearly	2	2

[a]CQC rating changed from 'Good' to 'Requires Improvement' at the start of the observation period

"…you can only keep them as safe as you can. There will always be falls. I was always taught that if they're not falling then they're not living. Because they're not moving around, you see?" (HCW28-interview).

One response to managing risk was to restrict clients' access to more risky or hazardous parts of the home:

'…Angela reminds Betty that her bedroom is now downstairs. Although jovial, Betty compares this to a dog being locked out of its room. Angela reminds Betty that her cousin Cliff had asked for this in order to keep her safe.' (Fieldnote).

Theme 2—Independence and identity

We saw and heard how homecare workers could use their often extensive knowledge about a client, their identity and wishes, to enable independence through offering meaningful choices and involvement in decision-making. Our two sub-themes explore: (1) understanding and valuing the client's identity and (2) mechanisms homecare workers used to help clients stay involved and making choices.

Subtheme 1: Understanding the client Acknowledging the personhood of people living with dementia was a prerequisite to enabling independence:

"We all had talents before dementia; we don't suddenly lose those talents overnight when we've got a diagnosis. And to remember that we were once a working person and a totally capable person. So to remember that there's been a person there that still can do things." (PLwD17-interview)

Being able to connect the past with clients' present lives was important for homecare workers; to be able *"to see their clients… to have some understanding of where they have come from"* (FC11-interview). Care provided in clients' homes, surrounded by their life memories and possessions facilitated this:

"We have a chap who… he was one of the first British soldiers to get captured and he spent the whole of the war in a prisoner of war camp. And he got out the photographs and he showed me… he could sit and talk for hours and hours and it obviously made him very happy… so it was always a good starting point for the homecare workers." (HCM001–interview)

In some observations, there was a sense that the client's identity and personhood were becoming challenged or lost, for example where homecare workers used infantilising language or behaviour. In the example below, the client was able to challenge this:

'Amy tells Beth that she's going to "give her little feety a wash now", to which Beth exclaims "I don't have a little feety, I have a foot!".' (Fieldnote)

Subtheme 2: Staying involved and making choices

We observed homecare workers supporting clients to actively participate in their care; for example, by simplifying or breaking down tasks. The examples below highlight the effect of different approaches taken by two different homecare workers with the same client:

'Amy told Beth they were going to wash her face. As she begins, Beth asks what she's doing with her face and Amy explains again. Beth says that she's not used to being washed and dressed by other people, she's used to doing it herself and begins to cry.' (Fieldnote).

'Alice told Beth they were going to wash her hands and then asked Beth if she would like to try washing herself as it 'might be good for her' to do this… Beth was able to use the flannel to wash most of her upper body, while Alice provided step-by-step instruction to Beth which she was able to follow–e.g. "now use this hand and wash under this arm", while touching each to guide Beth.' (Fieldnote).

In interviews, all participant groups highlighted the importance of involving people living with dementia in everyday tasks, even *"if they can't do it in a way that we expect it"* (HCSS02-interview). Often, this involved establishing relationships of interdependence and making required adaptations:

"I think the majority of people would still want to do things for themselves. So, it's what you can advise the person, like if the person can't tie their shoelaces anymore, then advise them and the family to get slip-on shoes." (PLwD17-interview).

Care approaches that enabled active participation in tasks and meaningful choice were observed to facilitate independence, but these could be overshadowed by time constraints, or a perceived obligation to provide the 'right care', particularly with clients whose abilities to participate in tasks and express choices were declining:

'Anya says to Belinda "go on eat your food". Belinda is eating her cereal but slowly. She says to Belinda, "go on eat it", she takes the spoon out of Belinda's hand and stirs the cereal and says again "go on eat it".' (Fieldnote).

'Angela asks if Betty would like a drink and she chooses both squash and coffee. Angela says she has already had coffee, she can have a lemon tea later on instead.' (Fieldnote)

Theme 3–Independence and empowerment

We saw how homecare workers advocated for their clients, ensuring the client's voice remained central to the care they received. This was often enabled by homecare workers, family carers and the person living with dementia working in collaboration:

"It's a three-way street… Between the carer, the client and the family. As long as the family is wanting to put the input in, that in turn helps us, which then in turn allows us to do that bit extra for our client." (HCW17-interview).

When this three-way relationship worked well, it could strengthen the voice of the person living with dementia:

"I think there's something about making sure the person with dementia has a voice, and not talking for them, even if their voice sometimes is very muddled." (HSCP17-interview)

Most clients observed were not able to make all their own decisions about care, with family carers frequently substituting as decision-makers. Homecare workers often felt unsure of whether and how to challenge or question proxy decisions with which they disagreed, as, while privileging the client's voice might be construed as supporting their independence, it could also be seen as directly challenging the family carer's authority:

'In the hallway, Cameron tells Alyssa that Beth had just said she didn't want to get out of bed today, but they should ignore that and get her in her chair. He added that if this was too problematic, the occupational therapist had said to just leave her in bed.' (Fieldnote).

"I know you've got to respect the families' choices as well, but I think the client's choices are important and I think you've just got to do things for the better of the client for what is going to be more beneficial to them." (HCW20-interview).

There seemed a fine-line for homecare workers between providing support with *"a bit of diplomacy"* (HCW23-interview) and stepping out of place with family carers. One homecare worker who was observed taking on excessive responsibilities for her client at the request of family carers, was later asked to leave by the family for becoming too involved in the client's home:

'Angela can no longer see Betty and must not return to her house to say goodbye; she is upset and concerned for Betty as she didn't have a chance to tell her she wouldn't be coming back.' (Fieldnote).

Though we only heard one perspective on this decision, the sudden dismissal *'after providing such committed care to Betty for over two years' (fieldnote)*, illustrates the insecurity of the homecare worker role. Other homecare workers described feeling powerless to influence their client's living situation:

'Anna says that she fears Beatrice will not have the strength to hold herself up or walk after being in bed for one week. She says that the social services' decision to keep Beatrice in bed has "completely taken everything away from her" and feels there is nothing they as homecare workers can do about it.' (Fieldnote).

Whilst many homecare workers felt they could draw on support from agency managers, they may still be hindered by the power dynamics involved in homecare and the insecure position of homecare workers within the client's multidisciplinary care. This, in addition to the vulnerability of the role, may be a source of stress for homecare workers when they wish to advocate for what they believe to be in their client's best interest.

Discussion

Main findings

In responding to our aim of exploring how homecare workers support or inhibit independence in people living with dementia, we observed the familiarity of home as an enabler, and explored how adaptations can facilitate necessary and often safer care, yet depersonalise the home. Homecare is delivered amongst clients' life possessions, giving homecare workers insight into clients' identities. Through familiarity with the client and their functional abilities, care approaches that enabled active participation in tasks, and collaborative working with clients and family carers in decision-making, we saw how homecare workers could advocate for the client's 'voice'. However, they could be unsure how to do so meaningfully with clients who have more advanced dementia, and whether and how to advocate with proxy decision-makers, amongst whom they could feel powerless.

Practice implications

Cahill [24] stated that changes to facilitate homecare should not reduce autonomy, independence, dignity, nor heighten changes to the self for people living with dementia. In practice, adaptations can involve trade-offs between these values and facilitating care that enables independence [25, 26]. Our findings illustrate the importance of minimising environmental changes and considering their potential impact carefully. We posit that care that is person-centred need also be home-centred, respecting the client's home as an extension of self. Reconstruction of the private home into a place of work has been discussed with other long-term care recipients [27]. We observed how homecare workers and the delivery of homecare could blur boundaries between the client's private space and the homecare worker's workplace; for example, where one homecare worker stored her bike in a client's hallway whilst on holiday. This must be considered in the context of homecare, where homecare workers typically work in isolation and have no shared place of work [28].

Engaging clients living with dementia in roles and tasks associated with the self reaffirms their sense of self identity [29]. Our observation of a client living with dementia challenging a homecare worker who infantilised her, highlights the client's awareness or 'continuity' of self [30]. NHS England's Well Pathway for Dementia [31] and other national initiatives stress the importance of promoting independence for people living with dementia, and enabling meaningful care [32]. We observed that the extent to which this was possible was limited by time-constraints and how providing people living with more severe dementia with meaningful choices was particularly challenging.

Rønning [33] described the need to find a balance between independence, dependence and interdependence. Interdependence, its intricacies and complexities, was evident in our observations. Where it is possible for homecare workers to establish a relationship of interdependence with clients living with dementia and their family carers as a team, there may be associated benefits such as prolonged functional abilities, decision-making and acknowledgement of important social relationships [13, 34–37]. Participants highlighted the importance of relationships being negotiated in a way that enabled the client's voice to be heard; our observations illustrated some of the frustrations experienced when the, at times, delicate support network that supported this interdependence was stressed or unbalanced. Scales and colleagues [38] argued that empowerment of care staff to provide flexible, person-centred care requires wider-level practice change beyond the current power constructs that influence dementia care. Many homecare workers know their clients living with dementia very well, and they may be in a unique position to advocate. Yet, in our

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observations, homecare workers often felt unable to do so. Powerlessness of care staff has been explored in residential settings, whereby organisational rules and demands often take precedence over person-centred care, resulting in some staff breaking rules to promote individualised care for residents [38–40]. Our findings extend this to show the vulnerability of homecare workers' position and limited power within the structure of homecare (see also Manthorpe et al. [41]). Professionalisation of the workforce is a potential, yet widely debated solution to improve societal and professional status of the homecare workforce [38, 42, 43].

Strengths and limitations

Our findings build on an important but under-researched area, exploring independence and homecare for people living with dementia. We represented diverse participant perspectives to explore our research question. Participant observations allowed us to capture the lived experience of homecare through the eyes of both the care provider and receiver; and the subjective experiences of people living with more severe dementia that are seldom researched.

Whilst we sought to represent diversity in CQC ratings of homecare providers, our sample consisted of agencies predominantly rated 'Good'. This is reflective of providers in England: 80% were rated 'Good' in 2020 [44]. In our recruitment process, agency managers selected homecare workers to participate in the study which may have entailed bias in selection of the 'best' care workers to reflect the agency positively. To minimise this, we asked agency managers to ask all eligible homecare workers who supported clients living with dementia. Our study was limited by situations we were able to observe (i.e. we only observed day-time visits), as well as the potential for the Hawthorne effect on those observed [45]. We did not collect quantitative data so cannot quantify the severity of dementia or of neuropsychiatric symptoms, however, we explored the varied lived experiences of people living with dementia being observed within our qualitative analysis.

Future research

Homecare for people living with dementia should continue to be explored through inclusive methods of data collection. Our study, in addition to previous research [16], found ethnographic participant observations were well-suited to capturing the lived-experiences of people living with dementia, including people who lack decision-making capacity, in the private setting of their home. Participant observations of care delivered in the home highlighted important considerations about the home environment itself and the way homecare workers interact with the home. The impact of the built environment on people living with dementia has been studied in residential settings [48], but less is known about the impact of the home environment on care provision.

Conclusion

We propose that care that is person-centred is also home-centred, respecting the sanctity and familiarity of the client's home as an extension of self. Homecare workers can support clients living with dementia to live at home as independently as possible by acknowledging and valuing their existing identity, facilitating involvement in tasks and decision-making, and working collaboratively with clients and family carers to make deliver care with the client's 'voice' at the centre. Interdependence may be the more optimal concept to strive for with clients living with dementia, particularly with

Table 5 Semi-structured interview topic guide

Participant topic guide	Questions related to independence at home in people living with dementia
Family caregivers	To what extent is [the person you care for] currently able to live independently at home?
	What do you find independence means for the person you care for? What do you feel being independent looks like for them?
	Can you think of a time since [the person you care for] has had memory problems, when they have/have not been able to achieve or do something independently that has been important/difficult for them? What happened? What made it easier/harder?
	What makes it harder/easier for the person you care for to live independently at home?
Homecare staff and Health and Social Care Professionals	What do you find independence means for your clients with dementia? What do you feel being independent looks like for them?
	Can you think of a time when a client with dementia has been/has not been able to achieve or do something independently that has been particularly important/difficult for them? What happened?
	What makes it harder/easier for your clients with dementia to live independently at home?
Person Living with dementia	What do you do to live independently at home? Do you get any help from anyone else (paid carer/family member)? What do they do?
	What can make it harder/easier to stay independent?

clients whose ability to express choices and make decisions is declining. Homecare workers could hold an important position in care networks, though their potential to achieve this is often limited by their position within power structures; we consider professionalisation of the workforce as a potential solution to address these issues.

Appendix A

(See Table 5).

Appendix B

Semi-structured participant observation guide

Guidance: areas of interest to keep in mind during the observation:

1. **A practical overview of the visit**

   a) record the time at which the home carer arrives and leaves the client's home
   b) who is present
   c) the environment in which the care is being delivered including physical layout, decor and cleanliness

   d) "atmosphere" including general feelings about tension, is it welcoming, comfortable etc.
   e) the tasks that are delivered

2. Interactions and responses of home carers with clients and others

   a) interactions and responses between the home carer and the client with dementia
   b) interactions and responses between the home carer and others who may be present

      o positive, negative and neutral interactions/responses
      o support of independence/choice/autonomy where possible
      o challenges to independence (e.g. symptoms of distress, refusal of care or risks) and responses to it where this occurs, and whether these strategies are effective in resolving distress and enabling necessary care to be given
      o emotional responses, strategies and resources used (e.g. practical, social, spiritual)

   c) how client (including behaviour, language, ethnicity and culture), family carer, home carer and/or management and organisational factors impact on care provided

Table 6 Data collection process of participant observations

Participant observation
We approached managers from a purposively sampled selection of homecare agencies that participated in the qualitative interviews, in addition to other selected agencies to take part in the participant observations. We provided agency managers with a participant information sheet.
ML, AB and JBD visited agencies where the manager expressed interest in the research, and answered any questions. Managers provided written informed consent for their agency to take part in the observations and completed a questionnaire about their agency.
Each of the consented homecare agencies were assigned to one of the researcher-observers – ML, AB or JBD - who were responsible for conducting all observations with that agency.
Agency managers identified homecare workers who supported at least one client living with dementia and provided them with a participant information sheet. They met with a researcher-observer to ask any questions, provide written informed consent and complete a demographic questionnaire.
Agency managers worked together with the homecare workers to identify and contact their clients living with dementia to participate in the observations. Managers firstly contacted the client with dementia or their family carer by telephone to explain the research. Managers and homecare workers informed the researcher-observers about the client's capacity and ability to provide consent.
The researcher-observer visited the homes of the clients living with dementia alongside their homecare worker. ML, AB and JBD received training to assess capacity of the person living with dementia. Clients who had capacity provided written informed consent. For those who were deemed to lack capacity to make an informed decision, we sought assent from a family carer either in person or via postal form.
The researcher-observer worked with the homecare worker to plan a schedule for observing them with their consented clients with dementia. We aimed to observe a range of homecare visit lengths, types of visits and tasks carried out (i.e. personal care, support outside the home, interactions with others present during the homecare visits), as well as interactions between homecare workers and agency staff.
One to two visits termed 'familiarisation visits' were carried out where homecare was observed without the researcher-observer taking any fieldnotes, aiming to foster rapport. Contextual information was sought, including any relevant background information. Notes were typed up after the visit.
Up to five further observation visits were carried out with each homecare worker and client. Researcher-observers took brief fieldnotes which were typed up no more than 48 hours later and used an ethno-interview technique (likened to naturalistic conversation). Written consent was obtained for any persons present during visits including other homecare workers, healthcare professionals and family members.

d) whether additional needs arise, either stated by the person with dementia, family carer or home carer and how these are managed.

e) references to client or family carer goals or priorities, how these emerge and how they are acknowledged or not.

f) general thoughts and feelings about the care being delivered and how the care provided enables or disables independence

g) how your presence as a non-participant observer may have influenced your observations

Appendix C

(Table 6).

Declarations

Conflict of interest On behalf of all authors, the corresponding author states that there are no conflicts of interest.

Ethics approval London (Camden and King's Cross) National Research Ethics Committee approved the study (reference: 17/LO/1713) in November 2017.

Consent to participate Participants with capacity to consent provided written informed consent. For people living with dementia without capacity to consent, written consent was sought from an identified personal consultee following the Mental Capacity Act (England & Wales) 2005 provisions.

Consent for publication All participant data presented in this paper have been anonymised.

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I submitted and presented this 'think-piece' to the Qualitative Health Research Network workshop on Truth, Trust and Research in Health and Social Care in 2020.

Title: Gaining trust to observe truth: methodological complexities as an outside observer

Ethnographic research applied to health and social care has the ability to illuminate a range of perspectives adding richness to our understanding and interpretation of relationships, behaviours and social interactions (Sharkey & Larsen, 2005). Participant observations are central to ethnographic approaches and require the researcher to become immersed in the field. There is no standardised observation method and variations exist in the extent to which the observer engages with the population of interest (i.e. their level of 'participation') as well as how they enter into the observer relationship. For example, the observer may have a dual role as both a nurse and a researcher observing in a clinical setting; with the benefit of pre-established familiarity in the field and trust with participants (Watts, 2011). For researchers entering the field as an outside observer (i.e. no previous connection with the population or setting of interest), prolonged participation may be necessary to develop trust. However, ethnographic observations within health and social care research seldom have the luxury of time and rapid approaches have been adopted to respond to more immediate challenges (Vindrola-Padros & Vindrola-Padros, 2018); hence prolonged participation is rarely possible. The outside observer must find other ways to develop familiarity and build trusting relationships with their participants to attain 'truthful' observations.

Our research aimed to explore how homecare workers can support independence in people with dementia through interviews and participant observations. Observing care in the home has greater methodological complexities than care provided in hospital or residential settings where the majority of ethnographic healthcare research has taken place. When in receipt of homecare, the home transforms into something of a third space incorporating a private, domestic space for the care recipient, and a workplace for the homecare worker. Familiar and trusting relationships often develop between homecare workers, clients with dementia and their family carers. Gaining the trust of our participants was necessary to capture a more 'true' representation of care provision for people living with dementia at home, and the trusting relationships that form between participants.

Transitioning from an outsider to the inside requires skilled negotiation in order to establish and maintain rapport (Pitts & Miller-Day, 2007). We aimed to foster rapport by introducing familiarisation visits before our fieldnote observations began; doing so is also considered a key methodological strength when observing people with dementia (MacLaren, Nelson, Wilkinson, & Taylor, 2017). In these visits, the observer viewed the homecare visit without taking any fieldnotes with the aim of enabling participants to become familiar with the observer's presence and to normalise the experience of care provision/receipt being observed by an outsider. These visits also enabled the observers to learn of any concerns from homecare workers of their work being scrutinised, as well as worries from clients and family carers about their 'favourite' homecare worker being 'taken away' if the observations portrayed them in a negative light. We managed these concerns by reminding participants that the purpose of our observations was not to portray 'good' or 'bad' care. However, we were clear about our duty to report unprofessional behaviour or where any persons involved were deemed to be at risk of harm.

Beyond the familiarisation visits, we continued to build trust and rapport throughout the time spent with homecare workers and their clients, as well as in interactions with homecare managers.

Some homecare workers and clients were comfortable with the observer simply sitting and watching, while others wanted to engage with the observer and get to know them personally. As the lead author, I reflected upon this as the need for the observer to share parts of the self, in order to gain the trust of those being observed. I also spent more time observing one agency in particular, where I was invited by the homecare manager to sit in the agency office during breaks. This additional time in the office was crucial to the shift from outside observer to insider and facilitated a more trusting relationship with the homecare manager; who was initially only selecting the 'best' care workers to be observed. Once trust was established, I was able to observe homecare workers who were new to the caring profession and had yet to complete their training and those whose motivations to provide care were a stepping stone to a more desired career path.

Moreover, our observations enabled us to consider the concept of truth-telling with people living with dementia, or in contrast, deception and its potential impact on independence. 'Therapeutic lying' is often deemed acceptable when in the client's best interests (Elvish, James, & Milne, 2010). We observed this from both family carers and homecare workers where the truth was withheld from clients if the reality would cause upset or pain, such as when clients asked where a deceased loved one was. One family carer wanted to withhold the client's dementia diagnosis from them to prevent further confusion, which the homecare worker agreed to uphold. Although the concept of truth-telling with people with dementia has been explored retrospectively through survey and interview data, participant observations enabled us to capture the complex reality of truth-telling in the context of care provision for people living with dementia at home, with homecare workers having to negotiate this moral and relational complexity.

In this paper, we have put forward the idea that the observer must gain the trust of their participants in order to capture 'truer' observations of relationships and interactions. We have also discussed the phenomenon of truth-telling observed naturalistically with people living with dementia. We conclude in highlighting that although prolonged participant observations are seldom possible in health and social care research, attempts to increase familiarity and therefore trust between the observer and those observed can enhance the likelihood of capturing 'truer' reflections of the phenomena of interest. However, we must reflect on the authenticity of capturing 'truth' in observations; if we consider Hammersley's (1992) notion that 'there is not a single valid description of a situation' we can question - *if another had been there, would they have seen what I saw?*