Proximities of Care: Exploring the spatial relations of voluntary and technological support for those living with dementia

Thesis submitted in accordance with the requirements of the University of Liverpool
for the degree of Doctor in Philosophy by Yelena Mikhaylova-O'Connell

2 January 2020

Abstract

This thesis presents a qualitative case study of responses of people living with dementia, carers, voluntary social care providers and technology developers to the community turn in care and dementia care provision supported by technological innovations. Against the backdrop of reductions to public spending on social care in the UK, technologically supported care is being offered as a solution to the current rise in the unmet support needs among those living with dementia. Drawing on theoretical frameworks of critical geographies of age, care giving and voluntarism, this research explores how the notion and practices of care are reshaped by technological innovations and voluntary activity. In-depth interviews and observations with people living with dementia, their carers, technology developers, volunteer befrienders and professionals provide rich insight into the blurring of the boundaries between care, friendship and befriending, the role of care technologies in supporting independent living, and uneven geographies of availability of technological care solutions.

The thesis shows that older people living with dementia have positive views on care technologies, particularly when support with setting up and learning how to use them is available. At the same time, findings reveal a concern among people with dementia about the reduction in human contact which could follow from the scale up and spread of care technologies. The thesis extends the current knowledge base relating to technology use by older people with dementia by developing particular understandings of how and why certain care technologies are adopted while others are abandoned. Findings are expected to contribute to the development of care practice around the use of voluntary and technological means to support people with dementia and carers in the community.

Confidentiality statement

Pseudonyms have been used throughout the thesis to protect the confidentiality of research participants and the case partner organisation that hosted the study.

Acknowledgements

I would like to take this opportunity to thank my research participants, whose identities I have kept anonymised to ensure confidentiality of personal data, but without whose wholehearted support this research would not have happened. Their stories and experiences not only formed the basis for this research, but also enriched my own life experience and understanding. I am also indebted to my PhD CASE partner organisation, a registered charity and social enterprise based in Liverpool which has been providing community based support, both locally and nationally, for a century. I would like to thank the members of staff at the organisation's dementia services for kindly helping me to recruit interview participants. I would also like to thank the Economic and Social Research Council who funded this work.

I am sincerely grateful to my supervisors, Dr Bethan Evans and Dr Mark Riley, whose patience, kindness, understanding and consistently constructive feedback have made it possible for me to complete this study.

Finally, I would like to thank my wonderful family for never failing to support me and always believing in me.

Contents

List of Tables

Chapter One: Introduction

1.1. Background to the study

The word ‘dementia’ is used as an umbrella term for a number of diseases and neurological conditions such as the Alzheimer’s disease and Parkinson’s disease, the symptoms include loss of concentration, problems with memory, cognition, reasoning mood and behaviour (Department of Health, 2015). An individual with dementia experiences progressive losses – physical, social and psychological, and currently no cure for dementia exists (Cahill et al, 2007). People with advanced dementia may become bed-bound, incontinent and unable to speak and have complex needs requiring round the clock care (Kupeli et al, 2018). Stories about dementia and dementia care have become increasingly common in the UK media (Hill, 2019; BBC, 2019), as the population ages and the number of people living with dementia in the UK reaches 800 000, predicted to reach 1.2 million in 2040 (Ahmadi-Abhari et al, 2017). In Liverpool, meeting the demand for care provision has been described by the city’s mayor as a ‘significant challenge’, and the city council reported that it spends nearly £50m per year on residential and nursing care for people living with dementia, and additional £11m on dementia and memory loss services (Tyrrell, 2019).

Despite the attention dementia care has received nationally, the pressing need for research into experiences of people with dementia and carers remains (Department of Health, 2015; Gibson et al, 2016; Orgeta et al, 2019). People living with dementia and family carers continue to face a range of challenges, including not receiving a timely diagnosis, the lack of availability of services offering post-diagnostic support, patchy quality of respite care provision, and often poor quality of care in residential and nursing homes (Robinson, Tang and Taylor, 2015; Bunn et al, 2015; Sutcliffe et al, 2015). The system of support for people with dementia and carers has been described by campaigners as ‘broken’, ‘unfair’ and ‘unsustainable’ (Alzheimer’s Society, no date). It has been argued, that the currently unfolding crisis in dementia care mirrors the crisis in adult social care in England (Alderwick et al, 2019).The crises are characterised by increasing numbers of older people unable to access social care; cuts to publicly funded care resulting in geographic disparities in care provision; diminishing capacity of health and care services to meet the increase in demand for care from people with complex conditions, such as dementia (Care Quality Commission, 2018; Alderwick et al, 2019).

While the search for a cure continues, a raft of documents focusing on improving the lives and care of people with dementia has been published by the governments of 3 nations (see the Prime Minister's Challenge on Dementia 2020 (2015); Dementia Action Plan for Wales 2018 – 2022 (2018), and non-governmental organisations (see Age UK's Living Well with Dementia Position Paper (2016); Alzheimer's Society's Hidden No More: Dementia and Disability report (2019). The documents outline the growing challenge of dementia and its impact on the national, regional and local economy, health and care services, communities and individuals living with dementia, and their family members. A closer analysis of the policy documents reveals that they share a vision of the society where the right of people with dementia to receive high quality care from the point of the diagnosis through to end of life care is central to all care provision (Department of Health, 2015; Welsh Government, 2018). Furthermore, the documents propose a number of overarching outcomes which will support the implementation of the vision, including achieving consistency of access and quality of care for all people affected by dementia; enabling people with dementia to live longer in their own homes independently; working in partnership with the voluntary sector, and enabling people's access to assistive technology, equipment and home adaptations. The policy documents also emphasise that increased research on issues that are important to people with dementia and their carers is essential to achieving the key outcomes (Department of Health, 2015).

Attending to the policy makers' calls for more research into dementia care delivery within home, increasing involvement of voluntary organisations in care provision, and assistive technologies for care, this ESRC funded study explores how these three interconnected trends currently prominent in dementia-related policy and practice in the UK affect people living with dementia and their carers.

Three of the key issues that have been raised regarding support for people living with dementia inform the research in this thesis. First, this thesis is concerned with the spaces in which people living with dementia receive care. With two thirds of people with dementia living at home, the largest part of care for the person with dementia is provided by family members (Dening, 2016). There are around 540,000 carers of people with dementia in England, and it has been estimated that one in three people will care for a person with dementia in their lifetime (Powell and Baker, 2019). Family carers' experiences of providing care are often described as unique because of the constant adaptation to the changing needs of the person with dementia, as well as to the changes to a carer's sense of personal identity, for example from being someone's partner, spouse, child to becoming the person's carer (Orr and Teo, 2015). This study therefore will explore the implications of home-based dementia care for people living with the condition and their carers, aiming to contribute to the growing field of geographical research into care provision within domestic environment.

Secondly, with costs of dementia to the UK economy estimated to reach £23 billion annually, more than the costs of cancer, heart disease or stroke, (Alzheimer's Society, 2019) the government and commissioners across health and care services have been looking for cost-effective solutions to provide dementia care. Carers and people with dementia having better access to assistive technologies was proposed as one of the solutions to this crisis in dementia care in the Prime Minister's Challenge on Dementia 2020 (2015). Indeed, one of the latest publications – a report produced as a result of an All Party Parliamentary Group's enquiry into dementia and disability (2019) states that as dementia is recognised as a disability, 'people with dementia are entitled to live independently in their own homes. They are also entitled to receive good quality, affordable supported housing, adaptations and technology.' (Alzheimer's Society, 2019: 35). As a result, technological solution to care provision, such as telecare and assistive technologies, emerged designed to address the needs of older people living at home (Milligan, Roberts and Mort, 2011). In national policy, the 'turn' towards technologically supported care provision was reflected in the establishment of the Technology Strategy Board (Innovate UK) in 2004 by the Department of Trade and Industry, whose aim was to 'work across government, business, and the research community removing barriers to innovation, bringing organisations together to focus on opportunities and investing in the development of new technology based products and services' (Her Majesty's Stationery Office, 2014: 1). The Board funded large scale 'demonstrator projects' nationally in order to test technological approaches to social challenges, one of such programmes titled dallas – delivering assisted-living lifestyles at scale was launched across 4 sites in 2012 with Liverpool receiving £3 million in funding to explore ‘ways of using innovative products, systems and services to promote well-being in their communities and provide high-quality health and care‘ (Her Majesty’s Stationery Office, 2014: 10). The voluntary organisation acting as a case partner in this study was a participant of dallas programme. By exploring interactions of people with dementia and carers with care technologies, this study will contribute to the geographical research around older people’s perceptions of technology items and telecare systems, and to the understanding of how new care technologies reshape the nature of care.

Thirdly, concurrent with calls for more technology are suggestions that there is a greater role for voluntary organisations and volunteers in the provision of dementia care. For instance, the Prime Minister’s Challenge on Dementia 2020 (2015) suggests a greater role for voluntary sector organisations in the design and delivery of dementia care services. According to the document, voluntary and community organisations can identify more people with dementia living in communities who have not been diagnosed, reach ‘seldom heard groups’, provide post-diagnosis support and engage with people with dementia and carers through a non-medicalised approach (2015: 25). This research will explore the relationships between volunteers, carers and people with dementia through a case study of a befriending scheme, contributing to geographical scholarship on the new distributions of responsibility for care between statutory and voluntary bodies and family carers. Furthermore, it will contribute to interdisciplinary debates on how the understandings of what constitutes care are reshaped through interrelationships between voluntary care providers, people with dementia and care technologies.

1.2. Research objectives

This research was undertaken at the intersection of the three trends described above, namely the growing numbers of people living with dementia, the challenges this has presented to the social care system in the UK, and the shift to voluntary and technologically supported care provision. The overarching aim of the research presented in this thesis is to explore the spatial interrelations of care in the context of increasing reliance on both voluntary and technological provision of care. The specific research objectives correspond to the challenges posed by the unfolding population trends and shifts in understanding of what constitutes care, the reframing of the responsibility for care provision evident in policy and services design, and the increasing presence of technologies in people's daily lives.

Specifically, the objectives of this study are:

1. To explore responses of people with dementia, carers and volunteers to the ‘community turn’ in care through a case study of a voluntary befriending scheme for those living with dementia

2. To explore new understandings of responsibility for care produced through the move to more voluntary and technologically delivered services

3. To examine the role of voluntary and technologically delivered care in facilitating independent living (or what's been termed ‘ageing in place’) and to understand particular forms of spatiality produced at the intersection of ‘ageing’, ‘care’ and ‘technology’.

1.3. Geographers' interest in care

Although geographers' have had a long-standing interest in the spatial distribution of older people and care delivery and services (Harper and Laws, 1995), ‘geographies of ageing’ have developed as a distinct field within human geography relatively recently - over the period of the last two decades (Skinner et al, 2014). Within this field, health and social geographers have engaged with the issues of ageing in relation to space and place (Andrews et al, 2013), and in particular with the spatialities of older people created through the negotiation of community life and places of care (Wiles, 2005; Milligan and Wiles, 2010; Golant, 2017). The impact of caregiving on identities of family carers of older people has been explored through the geographies of emotion (Milligan, 2005). In the UK, the shift to the wider and deeper involvement of voluntary organisations in social care provision has been critically examined through the lens of place (Fyfe and Milligan, 2003), and spatial scale (Milligan, 2007). Geographers have also identified that places and spaces of care are experienced differently by different groups, in particular highlighting the gendered nature of care provision in the context of the devolution of care to the community and home (Dyck, 2005).

Geographers have argued that social responses to dementia draw on the social and material networks available to the person within the social space of the community (Wiles et al, 2012b) as well as within the home (Dyck et al, 2005). The notions of autonomy in later life and independent ageing at home supported by technologies have been explored by geographers through Science and Technologies Studies-inspired approaches (Peine et al, 2015; Gomez, 2015). Geographical studies of home have critiqued and deconstructed the idea of domestic space as completely private (Burrell, 2014), arguing that public and private space is increasingly blurred when care is delivered in the older person’s home (Milligan, 2003; Brickell, 2012). This thesis contributes to the long-standing interest of geographers in places and spaces of care, the scholarship on particular spatialities of older people living with dementia, as well as to the recent interdisciplinary theoretical and empirical understandings of science, technology and ageing.

1.4. Approach to research (methods)

My research is rooted in social science research on dementia care and my selection of qualitative methods for the study was informed by the principles of inclusivity advocated by the social model of disability (Wilkinson, 2002). As such, this thesis aims, methodologically, to bring to the fore the experiences of people living with dementia and their family carers.

My study adopted a case study approach, working in collaboration with a case partner - a registered charity and social enterprise based in Liverpool and providing community services across a number of UK regions and countries (including Wales) for a century.

Research activities were carried out at two schemes run by the case partner – a volunteer befriending scheme for people with dementia based in Liverpool and a ‘companions’ service located in North Wales. Semi-structured interviews with people with dementia – recipients of the befriending and companionship services, their family carers, volunteer befrienders and case partner’s members of staff were carried out to gather their reflections on the meaning of independence in later life, ageing in place, expectations and responsibilities associated with care provision by family members, and the boundaries between friendship and ‘companionship’ provided by volunteers befrienders (see interview schedules in Appendices 1 - 5). In the interviews, some of which lasted for over 2 hours and included such practices as walking together or walking a participant’s pet dog, I asked people with dementia and family carers about their views on assistive technologies to support care, and about their daily interactions with technology items in their homes. Other participants selected for the study included professionals, such as health and care services commissioners, and technology developers associated with the case partner.

It must be noted, that while the study was ongoing, the Liverpool-based befriending scheme was discontinued because of the lack of funding, while the ‘companions service’ in North Wales continues to provide services to people with dementia. This did not affect the data collection process as this stage of the study had been completed before the scheme closed. I reflect on the case study approach, the data collection and analysis in detail in chapter Four.

1.5. Structure of the thesis

The remainder of the thesis is organised into eight chapters. Chapter Two discusses theoretical approaches to care rooted in feminist and disability scholarship on interdependency. Definitions of care and what constitutes ‘formal’ and ‘informal’ care are critically examined linking the notion of ‘familial obligation’ to the relational nature of care which is shaped by social, political and economic context in which it exists. The chapter moves on to describe the interrelationship between ageing and place from the geographical perspective bringing together literature on a range of specific spatialities constructed by older people. The meaning of home to people living with dementia is explored through the concepts of independence and changes in identity experienced by people in later life and conclude the chapter.

Chapter Three draws together literatures on technology and ageing focusing in particular on the process of biomedicalisation of later life through application of technological ‘solutions’ to the crisis of care. In chapter Four, I present the research design and discuss particular ethical challenges of conducting research with people with dementia and carers. I also discuss how qualitative case study approach and qualitative data collection methods have enabled me to bring to the fore the voices of my research participants living with dementia. The discussion chapter is split into three chapters – Five, Six and Seven. In chapter Five, I discuss competing views on care held by family carers and professionals, and the implication and impact on cares of the responsibilisation shift in care services design and provision. This discussion is followed by the perspectives of people living with dementia on what constitutes ‘care’ for them, including expectations they place on family carers balanced against their notions of living independently. Finally, the chapter addresses the ‘limits of care’ and the delineation between ‘friendship’ and ‘befriending’ in the context of care provision supported by volunteer befrienders.

Chapter Six discusses the ‘places of care’ through the analysis of the practices of ‘care in the community’, long-distance care supported by technologies, and ‘ageing in place’ based on the reflections from people with dementia and carers. In chapter Seven, I examine the views of technology developers on current and future solutions to dementia care, and how existing technologies are adopted, repurposed or abandoned by people with dementia, shaping and reshaping the practices of care themselves and affecting the interrelationships between people with dementia and human carers. Finally, chapter Eight outlines the key findings of the study, its theoretical contributions, and its recommendations to the policy and practice of dementia care. I argue that the concept of care should be broadened to include such aspect as ‘organisation’ of care which, as my research has shown, takes up a significant amount of family carers’ time, and for which little support is available from statutory services. I also reflect on the limitations of the study and future directions for geographical research into dementia, technologically supported care and the role of volunteers in care provision.

Chapter Two: Geographies of care

2.1.1. Introduction

This chapter progresses key debates within the geographical scholarship of care, studies of voluntarism, biomedical and social approaches to older age and long-term medical conditions, such as dementia, and science and technologies studies exploring the inter-relationships between older people and technologies of care. The review begins with section 2.1.2. tracing the development of debates within the field of geographies of care. In this section I argue that the recent shift in the provision of care from institutionalised settings into the community, as theorised by Lawson (2007), has resulted in the reframing of the responsibility for care. I move on to present the debates relating to the definition of care, arguing that care is central to all people's lives and outlining the blurred boundaries between the concepts of 'formal' and 'informal' care. The following sub-section explicates the concepts of care produced by feminist and disability study and argues that a relational approach can be useful to developing a better understanding of experiences of person with dementia. Sub-sections 2.1.6 – 2.1.10 present key debates about community based care in the context of the growing population of older people and reductions to public spending on health and social care provision.

In section 2.2. I turn to geographical literature on the intersection between age and place outlining critical approaches to the concept of 'successful ageing' (McHugh, 2003: 166). I argue that the biomedical model of dementia is the product of the biomedicalised view of older age and cognitive impairment. I then present perspectives of dementia stemming from the social model of disability, where the concepts of personhood (Kitwood, 1989) and citizenship (Bartlett and O'Connor, 2007) are central to understanding the disabling barriers in society experienced by people living with dementia.

2.1.2. Progress in the geographical scholarship of care

According to Kearns and Moon's (2002) overview of the progress within the scholarship on health geographies, human geography has undergone a number of significant transformations and shifts within relatively recent past. One such shift, described as a 'turn to culture' in human geography (Conradson, 2003: 452) produced the sub discipline of health geography, which had emerged from the broader field of medical geography around ten years prior to the publication of Kearns' and Moon's paper in 2002. Positioning geographies of care within the sub discipline of health geographies, Conradson (2003) emphasises the distinction between medical geography, concerned mostly with the study of the distribution and accessibility of services, and health and care geographies, which theorise care as a 'form of relation' in a variety of settings, producing unique spatialities (Conradson, 2003: 452). This is significant because considering together the interrelationships between place and people's experiences of health and care in place produces new understandings of what constitutes care. This thesis focuses on a set of care relationships produced through care provided by family members, volunteer befrienders and by the introduction of technological solutions and items purported to improve the lives of the cared for by enhancing their independent and reducing their reliance on human carers.

From the mid-1990s geographical scholarship on care has moved from the so termed 'traditional concerns' such as spatial distribution of health and care services, demographic ageing and migration of older populations to such areas of study as the relationship between place, health and care studied through critical theoretical lenses of humanism, feminism and postmodernism (Skinner et al, 2014:5)

The relational nature of care was highlighted by Harper and Laws' (1995) overview of progress in the development of geographical scholarship on ageing. The scholars echoed Rowles' (1986) earlier proposals to examine the interrelationship between care, place, proximity and older people's lives and experiences. Harper and Laws (1995) outlined emerging areas in the geographical research on age, such as the need to understand the complexity of care provision in both residential and community settings, the impact of distance on care relationship and on the carer in particular, and the role of private and non-profit sectors in care provision.

The more recent report by Andrews et al. (2007) reviews progress over the previous ten years of scholarship in geographical gerontology. Andrews et al (2007) call for more research with a focus on the impact of cultural and social processes in relation to older people, health, care and place. The authors' overview of geographical scholarship in the field of gerontology is framed by focus on the key geographical concepts of scale and place and their relevance to the ageing process and the changing experience of care in deinstitutionalised settings such as home and community.

Studies on the role of place in healthy ageing, how distance affects care provided by family members to older people and the attention to the influence of place, space and time on care have been gaining momentum over the past twenty years (Skinner et al, 2014). These studies have adopted a critical perspective on place in which the place has been viewed as problematic and contested (Wiles, 2005; Andrews et al, 2007). Place has been examined in relation to the ageing population, namely how different settings and environments, such as neighbourhoods, towns, residential care settings, hospitals and homes support, promote or hinder independence, health and wellbeing (Skinner et al, 2014). Research on home in particular has become one of the new pathways which have emerged from the critical scholarship on the role of place in older people's lives and experiences (Wiles, 2005; Skinner et al, 2014).

The recent shift in the provision of social supports from public to private sphere and the subsequent reframing of responsibility for care has resulted in its marginalised status within research and policy (Lawson, 2007). Although not a new concept to geographers, there are calls for care to become a more pressing concern in geographical scholarship because of its continuing marginalisation, which according to Lawson (2007) is a 'deeply political initiative' (2007: 5). As nongovernmental organisations, charities, communities, and families have fewer resources, the newly emerging 'landscapes of care' (Milligan and Wiles, 2010: 736) are often characterised by inequality and complexity. According to Lawson (2007), it is geographers' responsibility to debate and question who has access to care, who performs care and where it is delivered within the reshaped social and organisational spatialities.

2.1.3. Defining Care

Discussing the definition of care, Milligan and Wiles (2010) draw on a range of perspectives adopted by geographers and other social scientists studying the subject of caring for and about people. The authors' starting point is the critical assessment of the terms 'care' and 'care giving' through key concepts of autonomy, dependency and responsibility discussed in depth by disability scholars such as Oldman (2002) and Fine and Glendinning (2005), and through the prism of the feminist ethic of care as outlined in the works of Sevenhujisen (2003) and Lawson (2007). Defined simply, 'care is the provision of practical or emotional support' (Milligan and Wiles, 2010: 737). The emotional support element of care has also been defined by scholars as 'emotional labour' since both the delivery and receipt of care can be emotionally demanding as trust, privacy and vulnerability are exchanged and negotiated (Conradson, 2003: 451). Both physical and emotional relations and practices of care such as responsiveness, listening, feeding, changing, administering medication and so on, become interwoven with places and communities, producing the so termed 'social spaces', as theorised by human and cultural geographers (Sevenhuijsen, 2003; Conradson, 2003).

Care's 'relational nature' was previously highlighted by Robinson (1997: 120) who argued that 'a self' is defined though connection to others, and that life itself is dependent on connections and attachments (Robinson, 1997: 120). Milligan and Wiles (2010) develop the concept of the relationality of care further by describing care as a practise existing in the social spaces and necessitating interactions with a complex network of actors involved in the care process along with a commitment to the recipient of care. The network-like structure, maintain the authors (Milligan and Wiles, 2010), produces care flows travelling in multiple directions.

Milligan and Wiles (2010) identify three constitutive characteristics of care, namely interdependency, reciprocity and multidirectionality, which often intersect. In relationships between the carers and the cared for the exchanges of physical and affective care produce physical and emotional interdependencies, often underpinned by expressions of 'delayed reciprocity' (Milligan and Wiles, 2010: 737) between ageing parents and their children; the multidirectional nature of care is manifest in the frequent involvement of social networks rather than dyads in care provision. Pointing to the reciprocal nature of care, Bowlby (2012) states that reciprocity does not have to be understood as always immediate and sometimes may be expressed over long periods of time and in different care exchanges. Highlighting the active engagement of the care recipient in care process, Fine and Glendinning (2005) argue that care is a complex concept and practice which is not performed by one person alone and thus should not be defined using a narrow focus on a set of activities and tasks. Fine and Gelndinning (2005: 616) offer a definition of care underlined by the concept of 'reciprocal dependence' existing in a relationship between two or more people.

The notions of interdependence and mutuality are further explicated by Lawson (2007) who offers a theory of care rooted within the critical ethic of care perspective. Offering a critique of the neoliberal idea of an 'autonomous successful individual', Lawson (2007) points out that no one can thrive without care received throughout one's life. Many give care and take on responsibility for other people's wellbeing, as well as receiving care form others throughout life. In contrast to the neoliberal principles of individualism, competition, and a ''right'' price for everything' Lawson (2007: 2) foregrounds the public nature of care and argues that 'care is society's work'. By casting care as a private affair confined to the boundaries of home and delivered by families, neoliberal discourse produces groups of people 'in need of care – the infirm, the young/elderly, the dependent, the flawed' (Lawson, 2007: 3). The pursued solution to care provision is the shift of the responsibility for care from the state to the family which ignores the centrality of care to people's lives and societies, the fact everyone needs or gives care at some point (Sevenhuijsen, 2003; Lawson, 2007; Bowlby, 2012). Positing care as 'endemic' to nearly all social relations, Lawson (2007: 3) emphasises its reciprocal, coproduced and relational nature.

2.1.4. Formal and informal care

How care is defined and who provides care is determined by political, socio-economic and cultural constructions of care which also set the framework of carers' rights and responsibilities (Milligan and Power, 2010). While in some societies informal care provided by family is seen as the norm embedded within the notion of ‘familial obligation’ and situated at home (Milligan and Power, 2010: 568), in welfare regimes care until recently, has been constructed as the responsibility of the state and delivered in institutional settings as well as home. Since the mid-twentieth century the restructuring of welfare provision has been pursued by governments of many advanced capitalist countries in order to reduce the state’s responsibility for care (Milligan, 2001; Milligan and Power, 2010). An emergent mixed economy of care encompassing the state, the markets, the voluntary and informal sectors has resulted in most older people receiving most support from informal carers, usually family members, friends or neighbours (Wiles, 2003; Milligan and Wiles, 2010). The pluralism in care provision and the diversity of care exchanges have blurred the boundaries between formal and informal care (Milligan, 2006; Phillips, 2007; Bowlby, 2012; Williams and Crooks, 2008). For example, defining informal care as unpaid, and formal – as paid fails to address the fact that sometimes money is exchanged between the cared for and their family members, or as Bowlby (2012) points out, other forms of ‘reciprocation ‘in kind’, especially amongst low-income groups’ take place (2012: 2902).

Another aspect of care – its formal organisation and regulation demonstrates that there are more similarities than distinctions between the two types of care. Often informal carers take responsibility for organising formal care for their loved ones (Bowlby, 2012). Informal carers also have to organise their own routines and work patterns, and as Phillips (2007) points out, there is little that is informal about such arrangements. There are other similarities between the two domains, such as tasks which are often intimate and considered low status, questions around availability and quality, and work that is considered unskilled, hidden and silent (Phillips, 2007). Milligan’s (2006) study of informal care delivery in care home settings by family members demonstrated that family carers engaged in a wide range of tasks, including personal care, emotional work such as companionship and emotional support, and quality control work, such as checking the quality of care and monitoring medication and treatment. This, according to the scholar, indicates a further blurring of the boundaries between formal and informal care where the latter is delivered within ‘the semi-public space’ of a care home (Milligan, 2006: 330).

The relational nature of care means that it is embedded within and shaped by social, political and economic contexts, thus it is important to widen the terms in which it is understood – from giver and recipient to other factors such as gender, societal expectations of carers, ideas of kinship and obligation, proximity, as well as where care takes place (Milligan and Wiles, 2010; Power, 2010). Although geographers examine care through the lens of spatiality, focusing on the relationship between people, place and care, the extent to which the discourse of care influences 'the socio-spatial arrangements of care' also needs to be critically examined (Power, 2010). Welfare distribution and provision of support, according to Power (2010) is shaped by a society's interpretation of carers' roles and responsibilities and of how disability, older age and family care are conceptualised within political, economic and cultural discourses.

Exploring geographies of family care provided to older people, Joseph and Hallman (1998) consider two themes, firstly 'who does what', and secondly, how the type and frequency of assistance change under the conditions of increasing spatial separation (Joseph and Hallman, 1998: 632). The scholars have found evidence of the impact of gender on the patterns of care provision, with women willing to travel further and more often than men, demonstrating the so termed 'distance-decay effects' within the gendered geography of care (Joseph and Hallman, 1998: 631). The findings, according to the authors, are in accordance with broader evidence of care being a significant part of unpaid family work for women, found within social gerontological literature; however, by examining the geography of family care within the context of gender the scholars have illuminated how gendered geographies of care 'mirror the relationship between the public/private and male/female dichotomies (Joseph and Hallman, 1998: 638). Finally, Joseph and Hallman (1998) call for further active research into the spatiality of care with a particular focus on family carers within the broader research on health and ageing.

In the context of deinsitutionalisation in the UK characterised by the shift of care provision away from institutions to community and home, the debates about state and individual responsibility in relation to care, social and financial rights for carers are continuing (Power, 2010). As care work has historically been constructed as women's work, an extension of responsibility for maintaining home and family, new policies relating to the support of family and community care have a disproportionate impact on women who still predominate in informal care work (Milligan and Power, 2010). Moreover, Milligan and Power (2010) argue that the involvement of voluntary organisations in care provision also further reinforces the gendering of care, although this area requires further geographical research.

With the shift to family care, the notion of carer has been called into question, defined and redefined resulting in conflicting views (Power, 2010). While governmental policy provides a definition of the informal carer, often individuals do not necessarily self-identify as such (Milligan, 2001). Nevertheless, within the homespace family carers often take on tasks formerly assumed by paid professionals. Often, along with providing unpaid care to loved ones and performing a wide range of care-related tasks, such as physical and emotional support and care management, family carers may be involved in paid part-time or full-time employment. According to Williams and Crooks (2008), the increasing involvement of women in paid employment, smaller family sizes, increased mobility and family breakdown leave fewer carers able to commit to caregiving. In addition, some have to care for aged parents as well as young children. Williams and Crooks (2008) state that as a result of these trends, women's roles as unpaid carers are becoming 'increasingly complicated' and carer burnout has become widespread (Williams and Crooks, 2008: 244).

Although some scholars argue that male carers are playing a greater role in family care provision, it is also highlighted that the pace of change is very slow (Watson et al, 2004). Power's (2010) analysis of literature around male carers demonstrates that this aspect of care provision is under-researched. The scholar points to the complexity and ambiguity of gendered patterns of care and argues that who takes on the primary carer's role only emerges when 'people are pushed to make a choice', with other relatives often withdrawing 'once a main carer has been identified' (Power, 2010: 20). Power's standpoint echoes other scholars' perspectives on family and community care who note that often community care in practice means care provided by the family, which is often performed by one (female) family member (Milligan, 2001; Phillips, 2007).

2.1.5. (Inter)Dependency: feminist and disability studies perspectives of care

Meanings of care are diverse and complex, encompassing a range of conceptualisations present within different disciplines – from medical care, to care for objects and environment, to care as spirituality and altruism (Phillips, 2007). Ongoing debates around the concepts of care and dependency in feminist scholarship and disability studies are of importance to this project as they are linked to the ideas of independent living supported by care technologies, and micro-scales of home and community. In addition, it can be argued that although later life must not be 'equated with disability', some older people living with impairments have to rely on care and support services to a great extent (Oldman, 2002: 791).

Oldman (2002) discusses links between the conceptualisations of later life and disability studies drawing on parallels between older people as a social group and disabled people, such as the statistical correlation between disability and age, the possibility of a painful impairment in later life and discrimination faced by both groups. Another important point shared by both groups is the impact of disabling environment on people's lives. Oldman (2002) argues that many older people are disabled by their dwellings, sometimes trapped inside, experiencing misery and social isolation.

Disability scholars, including such authors as Thomas and Milligan (2018), Shakespeare et al. (2019) and Keyes et al. (2019) have recently argued that dementia should become one of the key areas of research within disability studies. As with broader debate in disability studies relating to the social model, this model may be useful as a way of drawing attention to the physical, social and political factors that disable people living with dementia, and can help move away from an overly medicalised model of disability. However, the social model does have limitations when it comes to degenerative conditions and is limited in its ability to account for the complexities of embodied experiences of living with dementia (Shakespeare et al, 2019). Instead, Shakespeare et al (2019: 1082) suggest that a relational model would "take an adequate and nuanced approach to dementia whereby there was both medical research into deficits and treatments, and action to remove social, attitudinal and architectural barriers". This approach, they argue, would also allow for activism that aims to empowering people living with dementia whilst simultaneously acknowledging that they need support. In a similar vein, Keyes et al., (2019: 300) suggest that an interdependence-based approach developed in disability studies scholarship would be a useful way to approach dementia because this approach recognises that all people are “engaged in caregiving as well as care-receiving relationships”.

Understanding how care is conceptualised in disability and feminist studies is instrumental to the examination of the relationship between care and dependency. The term care is seen as paternalistic and dependency-focused by disability scholars (Watson et al., 2004; Oldman, 2010; Power, 2010). Power (2010), for instance, maintains that care in the community has retained an institution’s characteristics such as ‘depersonalisation, rigidity of routine, block treatment, social distance, paternalism’ despite the change in the location of care provision (Power, 2010: 18). It is not the size of a care setting that defines an institution but rather its culture, thus even smaller community-based schemes may maintain a depersonalised care culture found in larger institutions. Even within a family setting the person receiving care may be perceived as dependent, passive and inert relative to carers, and thus despite the shift to community and family care the term ‘care’ itself is still associated by disability scholars with the lack of self-determination and autonomy, and central to the concept of disablism (Fine and Glendinning, 2005; Power, 2010; Milligan and Power, 2010).

Discussing the concept of care in relation to disabled and frail older people, Milligan and Power (2010) question whether the term should be used at all. Disabled people’s movement has called for the shift in the focus from care associated with dependency and confinement of disabled people to personal support (Watson et al., 2004; Milligan and Power, 2010). The proposed change in language replaces care with ‘personal assistance’ or ‘help’ reflecting the shift in power from the care provider to the recipient (Phillips, 2007: 28). Milligan and Power (2010) argue that this concept of care can be applied to any individual requiring support, however, in relation to older frail people personal support eventually will be replaced by care as frailty increases. The authors propose the notion of a ‘spectrum’ of care encompassing independence and personal support as well as dependence and care, with different spatialities of care occurring for people with different impairments (Milligan and Power, 2010: 581).

The term ‘carer’ has been replaced by the ‘Personal Assistant’ (PA), employed by the disabled person with the sum of money which the person controls and decides how to spend. Describing the role of the PA as ‘task-centred, involving response to instruction’ fulfilled by a person who does not ‘require repeated expressions of gratitude’ in a business-like arrangement, Watson et al (2004) argue that such relationships counter the view of disabled people as objects of care; instead, they are active recipients of assistance in control of their own lives. However, the independent living model based on the direct payment policies enabling people to employ own PAs may not be so appealing to older people experiencing extreme old age or an intellectual impairment, as acting as an employer under these circumstances may be overwhelming (Oldman, 2002; Fine and Glendinning, 2005; Milligan and Power, 2010;).

As women still constitute the vast majority of carers both paid and unpaid, care restructuring has had a profound effect on women involved in care provision, with paid carers experiencing lower pay and less employment security, and unpaid family carers shouldering the responsibility for care work in the community (Williams and Crooks, 2008; Power, 2010). According to Watson et al (2004), feminist critique of care centres around the notion that care work is ‘an activity to which women are naturally suited’ and thus continues to be ‘a source of women’s exploitation’ (Watson et al., 2004: 331). While the disability movement views the role of the PA as a step towards breaking the link between care and dependency, feminists argue that the arrangement drives down already low wages of predominantly female care workers (Power, 2010). The feminist standpoint on care focuses on placing a greater value on care work and affording better resources to those employed as carers and those providing unpaid care at home.

Another debated aspect found within the contradictory positions on care between women’s and disabled people’s movements is the emotional or affective component of care (Milligan and Wiles, 2010). Within disability scholarship the caring relationship is constructed as something instrumental, an interaction between the employer and the employee whereas the emotional component is downplayed, while feminist tradition has described care as emotional labour characterised by embodiment and affection (Watson et al, 2004; Milligan and Wiles, 2010). To address tensions existing between feminist and disability studies' conceptualisations of care Watson et al (2004) have developed a model based on the notion of interdependence. The scholars are proposing to move away from binary concepts of carers and dependent care recipients which, they argue, 'obscure reciprocity in human relationships' (Watson et al, 2004: 345). The authors highlight the importance of mutual need underpinning all caring activities and responsibilities which can be better understood by employing the concept of interdependency (Watson et al, 2004). The idea of mutuality as a means of challenging the dependency narrative is proposed by Milligan and Wiles (2010) who call for theorisations of care which encompass its capacity to produce a mutual sense of identity and self-worth.

Finally, Fine and Glendinning (2005) have argued that the challenge to the notion of dependency must come from the concept of care based on its multidirectional nature bound with the notion of interdependence produced by exchanges within care network taking place over time. The complex spatialities of care, encompassing human and spatial relations, norms around who should provide care, welfare arrangements and organisational structures form the so termed 'landscaped of care' as theorised by Milligan and Wiles (2010: 740).

2.1.6. Landscapes and spatialities of care

According to Phillips (2007: 104), geography is often 'invisible' in care literature even though it is central to how people experience care. Undoubtedly, geography impacts on the life of carer and care recipient to a great extent and in multiple ways (Power, 2010). For example according to Power (2010) spatial segregation to which people with disabilities, mental illness and older people have been subjected for purposes of care provision has shaped relationships with care providers, families and society in general. The spatial layout of cities coupled with an exclusionary 'attitudinal environment' continue to reinforce the marginalised status of older people and people with disabilities (Power, 2010: 22).

Under-researched areas focusing on the geographic experiences of older people in a range of environments, for example in their own homes or segregated long-term care facilities were identified by Rowles (1986) in the mid-1980s. Rowles called for a shift in the studies of geographies of care from institutions to home and community aiming to explicate the influence of spatial proximity on the assistance that older people may receive from their neighbours in the community. The efficiency of home and community based support, according to Rowles (1986), also needed attention. Since then, geographers have responded to Rowles' (1986) call. For example, Wiles (2005) has explored the theme of community-based care, in particular its implications for unpaid carers who are mostly female family members. Wiles' (2005) focus is on place as a process and a context which plays a role in shaping older people's experiences of the process of ageing and care. The continuous relationship between older persons and place is described by Wiles (2005) as 'mutually constitutive' with changes such as population ageing and desire for autonomy affecting social processes linked to the provision of support and independent living (Wiles, 2005: 102). To illustrate this, Wiles (2005) draws on the interrelationship between geographical proximity and care where more hours of assistance are provided by family members living with or near the person they care for.

In addition to this spatial factor Wiles (2005) discusses key social factors which determine the extent of care provision, such as gender, relationship, employment status and the frailty and increased dependence of the care recipient. Provision of care performed at micro level, such as at a person's home or the community is intertwined with the place itself affecting its symbolic and physical meaning, making the place a negotiated and complex process experienced differently by care providers and recipients (Wiles, 2005). Thus, home as a site of care becomes a place which is constantly negotiated by the older person who is adapting to the changing physical environment, to alterations to the position of family members who become carers, and to the blurring of the boundaries between the private and the public with health and care professionals providing care in what was formerly a private space.

Highlighting the complex nature of home as a site of care, Skinner et al (2014) outline a number of research areas to which geographers can contribute. First, the authors call on researchers to engage with the multiplicity of ways in which home influences older people's lives and experiences – from location and access to health and care, to enabling or hindering independence and ageing in place. Echoing Wiles' (2005) view of home as a place imbued with conflicting meanings, interpretations and demands, a place where comfort and privacy can be experienced alongside withdrawal and isolation, Skinner et al. (2014) argue that geographical enquiry into ageing must not separate older people from their environments but consider the ways in which place influences ageing and care.

In order to illuminate the relationships between care at distance and at proximity, Milligan and Wiles (2010) use the concept of 'landscapes of care'. This concept allows them to uncover the ways in which care is experienced at a range of scales, including home, neighbourhood and community. Scale is instrumental to understanding connections between places, with a scalar approach to care helping to uncover how policy decisions taken at national level are implemented at local level, and even how care is provided at home (Wiles, 2005). Exploring the connections between care and ageing in place, Andrews et al (2007) highlight the importance of enabling environments at a smaller spatial scale such as a remodelled town centre, a dwelling or a neighbourhood on older people's experiences of care. Discussing place, Andrews et al. (2007) stress that it should be seen as having an active role in the composition of social relations whose outcomes shape older people's lives and are shaped by them.

The focus on the micro-scale, according to Skinner et al (2014: 8) allows 'the subjective experience' of older people in a variety of care settings, including homes, retirement communities and residential settings to be foregrounded. Paying more attention to the ways older people are embedded in environments where care is received will enable researchers to understand how it is experienced (Milligan and Wiles, 2010; Skinner et al, 2014).

With the increase in the population of the 'old old', whose life expectancy has exceeded healthy life expectancy, the focus of policy on 'ageing in place' and the emergence of home and community as key sites of care provision, the familial and individual responsibility for care has been elevated over statutory support (Milligan, 2006: 320). While scholars agree that to a large extent community care is provided informally by family, friends and neighbours (Wiles, 2003), some studies have demonstrated that in reality care by the community often means ‘care by one individual’ (Milligan, 2001: 180). According to Power (2010) the idea of the ‘army of carers’ does not stand up to scrutiny as carers often work on their own, while community care often means family care without support (2010: 16).

Gleeson and Kearns’ (2001) critique of care in the community centres on the ‘idealised and singular construction of ‘community’ (2001: 69). Diverse views of what may constitute a community and varied social geographies present in the modern society render the notion of a cohesive caring community problematic. The scholars argue that networks forged artificially through care professionals are not likely to be sustainable (Gleeson and Kearns, 2001). Fostering the idea of care on an unwilling community, maintain the authors, may in reality result in ‘institutionalisation within the community’ leading to the collapse of the arrangement (Gleeson and Kearns, 2001: 77)

While the meaning of home may encompass the notions of identity, control, privacy, and security, its intersection with the construction of care by the state renders it a public place in which care is provided and experienced (Wiles, 2003). Experiences of care are often contradictory for care recipients and providers as their ‘temporal rhythms’ may be different (Wiles, 2003: 1309). Wiles (2003) calls on geographers to emphasise the importance of power dynamics within the home which take on a function of a site for care work in in addition to its primary function of a family dwelling. Exploring care provision within homespace Milligan (2000) argues that the blurring of the boundaries between public and private space is particularly evident within the home. Milligan (2000: 55) describes home as the ‘sole locus of formal and informal care provisioning’ as the shift of care provision into homespace has resulted in the lack of ‘alternative sites of caring’. Milligan (2000) notes that although carers welcome statutory support options available at home, they may experience profound changes engendered by the intrusion of public services into the private sphere, such as the loss of control and an increase in the care work load, as they try to navigate the complexity of the altered domestic space. If support required at home is extensive some carers and care-recipients may even experience ‘an institutionalization of the home’ (Milligan and Power, 2010: 575).

According to Phillips (2007) home, on the one hand, is an idealised place, a container for individual biography, while on the other hand, altered by formal care provision, it becomes a ‘non-place’ similar to an institution (2007: 109). While home may not be the ideal place for care, some residential settings may offer a home away from home as new forms of care, such as smart homes, are emerging (Phillips, 2007; Milligan and Power, 2010). Care technologies designed to enable older and disabled people to live more independently within the home are changing caring networks, bringing in new providers and workers. Their impact on who provides care and where is significant and cannot be accepted without further scrutiny (Milligan and Power, 2010). Some of the questions relating to care technologies are around their impact on the privacy of home, consent and data ownership, and these require further urgent attention (Milligan, 2009; Milligan and Power, 2010).

As new forms and places where care occurs emerge, scholars have called for further research into the intersections between place, care-giving, and responsibility for care (Milligan and Power, 2010). For example, echoing the caring network approach, Phillips (2007) emphasises the need for more flexibility in the way care locations are theorised as both spatial and social relations, including ‘the connectedness between people within the environment’ should be encompassed (Phillips, 2007: 119)

2.1.7. Restructuring of care in the context of demographic ageing and social care budget reduction

It has been argued that the current public spending cut backs and welfare budget reductions in the UK constitute the largest austerity measures since the Second World War (Tayor-Gooby, 2012; Mohan, 2012), with some scholars comparing the ongoing shrinking of social assistance to the nineteenth century Poor Law (Macnicol, 2015). The welfare state retrenchment initiated by various governments in developed countries in the 1970s and 1980s characterised by the offloading of welfare responsibilities to the non-state providers such as private markets, voluntary organisations, citizens and the community (Hanlon, Halseth and Ostry, 2011; Mohan. 2012), has affected all vulnerable groups, in particular older people dependent on publicly provided social care (Milligan, 2001). Budget cut backs affecting this particular population have manifested themselves in the 'shift in the location and mode of delivery of care' (Milligan, 2001: 1), that is - in the move of service provision from large publicly funded institutional environments towards small community-based locations producing specific geographies of care (Milligan, 2007). These variations and the resulting uneven landscapes of care delivery in the context of welfare reform are yet to be thoroughly addressed by geographers (Fyfe and Milligan, 2003; Wolch, 2006).

Specific research areas within the field of geographies of care have been highlighted by a number of scholars; for example, Milligan (2001) has called for geographers to focus on place and spatial levels when explicating aspects and outcomes of care provision restructuring. Milligan (2001) argues that although geographers have had a longstanding interest in welfare restructuring and care delivered in the community, studies have not yet fully addressed the links between geographical variations in care provision and the influence of place and local contexts on care supports. Milligan's (2001) analysis of geographies of deinstitutionalised care in the Scottish context has paved the way for further research into the interaction between conditions at the local level and broader social, cultural and political trends, emphasizing that such interaction has resulted in distinctive geographies of care characterised by significant variations in availability, access and experiences of care.

Under the conditions of welfare retrenchment and extensive restructuring of public services, where the state's responsibility for social care is offloaded to the private and voluntary sectors and communities, an individual's responsibility for one's own health and wellbeing becomes the focus of policy (Milligan, 2001; Lloyd et al., 2013). The so termed 'self-help message' intertwined with stereotypes of older people's dependency helps to create the discourse of self-reliance characterised by demands for funding constraints on social care and the fostering of the active ageing agenda (Lloyd et al., 2013: 330). According to Lloyd et al (2013), while the active ageing ethos may have a number of positive aspects, such as the drive to improve older people’s health and wellbeing, their inclusion in public life and the maintenance of functional health and independence, it may also be perceived as an opportunity for further reductions in publicly funded services. The adoption of the active ageing agenda by underfunded local authorities has coincided with deep cuts in service provision to older people with high support needs, whose ability to engage in activity is already limited (Lloyd et al., 2013). In the UK policy context the self-reliance ethos is reflected in the ‘personalisation agenda’ with its message of the individual choice, and the emphasis on individual responsibility for one’s own needs assessment (Lloyd et al.; 2013: 329). Although both the active ageing and the personalisation agendas are promoted by policy makers as a vehicle for exercising choice and control over one’s health, wellbeing and support services, in reality, as Lloyd et al have argued, they are no more than a ‘smokescreen’ for social care expenditure reductions (2013: 330). This view of the personalisation agenda is echoed by Beresford (2013) who has argued, that although personalisation is rooted in the disabled people’s movement championing the social model of disability and campaigning for direct payments, its ideological underpinnings are very different to the philosophy of independent living developed by the movement. According to Beresford (2013), unlike the grassroots Disabled People’s Movement which advanced the values of control and empowerment through a collective action, the personalisation agenda is closely linked with the idea of market driven welfare provision bound up with government public policy. Whereas the idea of disabled people as citizens with equal rights was central to the 1980s and 1990s campaigns for self-directed support and direct payments, the current move to personal budgets models the person as a consumer within an ‘exchange relationship’ devoid of emancipatory principles (Beresford, 2013: 91).

Although the personalisation agenda has promised to avoid the pitfalls associated with the implementation of the community care agenda in the 1980s and the direct payments initiative in the 1990s, such as slow progress, inertia, bureaucratisation and resistance of local authorities in some areas, the evidence suggests that it has so far failed to do so (Beresford, 2013; Lymbery, 2013). As Beresford (2013) has pointed out, recent studies with service users and carers have revealed that they primarily view personalisation as a vehicle for person-centred support, challenging paternalistic decision-making in support provision and institutionalising approaches to care. He argues that, just as the direct payments before them, personal budgets can play a significant part in the advancement of independent living. There are, however, a number of barriers to this, among them - inadequate social care funding rooted in the ‘deficit’ model rather than the spirit of independent living, and care culture still characterised by ‘continuing institutionalisation, control, paternalism and inflexibility in services’ (Beresford, 2013: 95). The author concludes that the personalisation agenda can either drive the liberation movement forward, similarly to the direct payments initiative developed by the disabled people’s campaign, or be used as a smokescreen for cost cutting, privatisation and continued over reliance on unpaid care.

Ferguson and Lavalette (2013) offer a more critical view of the personalisation agenda focused around neoliberal approaches to social care. They point to the climate of austerity in which personalisation reforms are taking place, arguing that the self-reliance and self-help message directed at vulnerable people and cash-strapped communities only serve the purpose of shifting care responsibility from the state to the individual. The empowering potential of person-centred approach has been subsumed, the authors argue, by the structural shift towards privatisation and marketization of social care and the increasing withdrawal of the state, set in motion by the neoliberal ideology (Ferguson and Lavalette, 2013). Analysing the personalisation agenda through the linguistic lens and discussing the origins of the term, Roulstone (2013) warns against an uncritical acceptance of the seemingly progressive language used by the proponents of the agenda. Terms, such as ‘empowerment’, ‘citizen control’, ‘emancipatory practice’, borrowed from the campaigns of the Disabled People’s Movement, may help to divert attention from the cuts and mask the expectations of self-provisioning in the context of austerity (Roulstone, 2013: 119).

Echoing Ferguson and Lavalette’s critique of the ‘neoliberal consumerism’ approach in the social care policy development (2013: 187), Roulstone (2013) argues that without the broader humane and equitable social support system personalisation is in danger of becoming a vehicle for further alienation and exclusion of the most vulnerable. Calling for further research into the practice and lived experience of personalisation, the author warns against the uncritical use of the term and the failure to challenge the existing neoliberal policy direction towards the ‘de-collectivised life’ and ‘enforced individualism’ (2013: 120).

The current transformation of the public services in Western capitalist societies has been described as more than a mere short-term budget rebalancing carried out in order to achieve a quick deficit reduction, rather the restructuring has been theorised as a systemic, ideologically driven and politically determined retrenchment (Taylor-Gooby, 2012; Ferguson and Lavalette, 2013; Skinner and Rosenberg, 2005). Taylor-Gooby’s (2012) analysis of the restructuring programme undertaken by the UK government in 2010 illustrates the move to a permanent new trajectory in state spending. Adopting Pierson’s (1994) classification of retrenchment into two distinctive categories - ‘programmatic’ and ‘systemic’ (Pierson, 1994: 15), where the former concerns spending cuts in the areas of public service provision, while the latter is directed at the achievement of profound changes to the context for current and future funding decisions, Taylor-Gooby (2012) argues that both types of retrenchment are being implemented in the UK. The author concludes that the game-changing systemic retrenchment will have a long-lasting and even permanent impact on all public sector services, immensely damaging the living standards for the most vulnerable.

What Taylor-Gooby (2012: 65) sees as ‘root and branch reform’ will see the entitlement to public support redesigned and restricted through the cuts in benefits for those of working age, including people with disabilities and older people, and the raising of pension ages. Consequently, social care will also undergo systemic transformations, as with the shift of responsibility for provision away from the state, it will be increasingly delivered by private actors, implementing charges-based business models as well as not-for-profit agencies, resulting in significant variations in quality and availability of services across the country.

Using the concept of social care as the central point of analysis of welfare state development, Daly and Lewis (2000) argue that it would be impossible to understand the current changes taking place in welfare states without looking at the concept of care, which the authors place at ‘the intersection of public and private’, including state, family and market provision, ‘formal and informal; paid and unpaid; and provision in the form of cash and services’ (Daly and Lewis, 2000: 282). Thus, according to Daly and Lewis

(2000), care as an analytical tool lends itself to the exploration of a range of significant developments within welfare states. These include the shift towards a mixed economy of welfare, which has seen the division of responsibility for care provision among different sectors, including the family, the voluntary sector and the market; the substantial changes to social rights of care recipients and carers, with those with most severe needs qualifying for provision, while those with available family carers being denied support; and the transformation of traditionally gendered social policy in the context of demographic ageing and the diminishing supply of family carers due to fewer women engaging in unpaid private care (Daly and Lewis, 2000) [1]. By broadening out the analytical potential of the concept of social care, Daly and Lewis (2000) have highlighted a gap in the scholarship on the embeddedness of care in the social and political economy of the welfare state.

Daly and Lewis' (2000) call for research into the interrelations between care and welfare state at macro- and micro- levels, encompassing the political economy of care provision by various sectors as well as individuals' experience of care, has been echoed by a number of scholars (see Milligan, 2001; Power, 2010). For instance, according to Milligan (2001), in order to examine a restructured geography of care, characterised by the move from the institutional to community based provision, geographers need to develop a research framework which would take into account the social, economic and political context in which care is delivered and experienced. The scholar calls for a particular attention to the multi-levelled contexts of care implementation, encompassing the national macro-environment and the individual micro-level (Milligan, 2001).

Power's (2010) analysis of welfare state regimes through the concept of care demonstrates that the diverse approaches to welfare and care provision across the world are developed as a result of the interrelationships between state, market, voluntary sector and family. Welfare allocation in Western capitalist states, according to Power (2010), is determined by a blend of social democratic and neoliberal ideological agendas, where the current and expected demographic pressures are employed to justify the adoption of cost-controlling measures such as means testing and tighter eligibility criteria, aimed primarily

---

[1] Feminist analysis of care as women's work, and of care provision becoming problematic for welfare states because of the following social and economic factors: changing norms about family responsibility and the role of women ('women are not available' Daly and Lewis (2000: 289); Power (2010:33) separation of male/female, public/private).

at vulnerable and dependent sections of populations. The author concludes that if the current trajectory of care provision in England continues to be defined by cuts and consumerist approaches to public services, the main responsibility for care provision will be placed on families with little support available from the state.

Undertaking a critical examination of the interrelationship between neoliberal welfare policy and older age Macnicol (2015) states that neoliberalism with its tenets of a free deregulated market, ‘a minimalist state’ and the preference for the ‘private provision of goods and services’, is ‘opposed to state welfare, believing that true welfare is best delivered through family, friends, neighbours, charities and private for-profit agencies’ (Macnicol, 2015: 14-15). Since the inception of this political agenda in the 1970s the welfare rights of older people have been under a persistent attack, with recent raises in state pension age and the push for older people to remain in employment in later life being a part of the transformation. Describing the unfolding changes as ‘the back to the future scenario’ where the current conceptualisation of older age echoes that of the pre-twentieth century, when the term ‘old’ was applied to ‘the oldest-old’ or those ‘extremely infirm’, Macnicol exposes a contradictory nature of today’s debate about ageing (2015: 2). On the one hand, argues the author, the radical transformation of the older age agenda has shifted the discourse around the meaning of older age towards the empowering language of anti-ageism, producing policies that tackle age discrimination; on the other hand, these positive changes have accompanied the curtailment of older people’s welfare rights, thus presenting population ageing as ‘both a cause for celebration and a potential catastrophe’ (Macnicol, 2015: 67).

The idea of older age as a looming crisis is rooted in the demographic concerns about population ageing which have been driving up the cost of welfare in all Western countries (Macnicol, 2015; Lloyd et al, 2014; Spijker and MacInnes, 2013). As for the first time people aged over 65 outnumber children under 15 years in the UK, with the proportion of over 65s having grown from one in 20 to around one in six over the past century (Spijker and MacInnes, 2013), economists and policy makers are framing the demographic trends as ‘unprecedented’ and ‘apocalyptic’ (Macnicol, 2015: 65). Substantial cuts to welfare spending and raising of the pension age are being legitimised by casting older people as an unaffordable fiscal burden and presenting their rising numbers as a threat to prosperity

(Mullan, 2000). The discussion of current demographic trends, as some scholars have argued, has not been entirely free of ideology, contaminated by the ‘crude demographic determinism’ (Macnicol, 2015: 21) and framed by the language of dependency (Lloyd et al, 2014).

2.1.8. Critiques of the old age dependency ratio

Studies of the current demographic drivers affecting the ageing agenda have highlighted the limitations of the old age dependency ratio widely used by policy makers (Lloyd et al, 2014; Macnicol, 2015; Spijker and MacInnes, 2013). The dependency ratio expresses the number of people who have reached the pension age of 65 relative to the number of working age adults aged between 16 and 64, theoretically demonstrating the proportion of the dependent economically inactive older people who have greater demands on health and welfare systems relative to ‘those who pay for them’ (Spijker and MacInnes, 2013: 1). The current ratio of 31% in England and Wales is predicted to rise to 37% by 2035 resulting in increased expenditure on pensions, health and social care (Spijker and MacInnes, 2013). One of the problems with the dependency ratio, according to Lloyd et al (2014), is the definition of economic (in)activity: although it is possible to calculate the number of people of different ages, the question of their contribution to the economy is rather more complex. Although presently in the UK one in 12 people over the age of 65 are in paid work, numbering 1.4 million in 2011, double the number from 20 years ago, being employed is only one of many ways to contribute (Lloyd et al, 2014). Unpaid work in the voluntary sector, child care provided by grandparents and the ‘spending power of the grey pound’ counter the narratives of inactivity and dependency (Spijker and MacInnes, 2013: 1). Unpicking the validity of the dependency ratio, Macnicol (2015: 1) critiques the definition of ‘old age’ as a stage of life after 65, pointing out that people age at different rates and therefore this arbitrary ‘demarcation line’ has ‘no biological or cognitive significance’. Another flaw of the dependency ratio composition highlighted by Macnicol (2015) is the focus on people of working age only at the time when many people of working age are actually not in work and can be classed as ‘dependents’. This limitation in the definition of the ‘working population’ was previously highlighted by Mullan (2000) whose study of the economic and social implications of ageing has critiqued the demographic alarmism permeating the contemporary ageing agenda. The author’s analysis challenges the legitimacy of the ‘crude’ dependency ratios based on the inclusion of those who do not work for physical, social or economic reasons (Mullan, 2000:124). The ‘real’ dependency ratio can be calculated if the impact of labour market fluctuations is taken into consideration (Mullan, 2000) and the size of the existent workforce with adjustments for age, gender, full-time and part-time work is used (Macnicol, 2015).

Spijker and MacInnes (2013) offer an alternative way of measuring dependent older populations, using the number of people actually employed rather than those of working age, relative to the number of older people with a remaining life expectancy of less than 15 years, as most acute health and care needs arise at this point in life. The authors’ own calculation has demonstrated a decrease in dependency by a third over the past 40 years and a projected further fall in the future before it stabilises (Spijker and MacInnes, 2013). They maintain that the population is in fact getting younger with ‘increasing numbers of people in work for every older person or child’ (Spijker and MacInnes, 2013: 2). Echoing Mullan’s (2000) conclusions about the impact of the so termed ‘demographic time bomb’ on health and social care systems, Spijker and MacInnes, (2013) suggest that apocalyptic demographic projections that cast older populations as an unaffordable financial burden are an exaggeration. While there is wide agreement among scholars that the UK will face demographic challenges in the coming years, the nature of these pressures is multifaceted and complex. For example, the anticipated increase in the demand for health and social care services is attributed to the progress in medical science and technology rising to the challenges of treating complex comorbid ‘age-related conditions’ (Spijker and MacInnes, 2013: 2). The reductions in public spending taking place in the environment of ‘the anti-welfarist cost cutting mood’ have resulted in the increased levels of permanent poverty among older people (Mullan, 2000: 93). The reduction of poverty, particularly among older women, and tackling social class inequalities as related to the retirement age and life expectancy differences are among key issues yet to be addressed by governments (Macnicol, 2015).

2.1.9. The reawakening of interest in the voluntary sector

The restructuring of social care provision in the UK as a response to demographic ageing has resulted in, as some scholars argue, the near collapse of the social care system (Ferguson and Lavalette, 2013). The social care crisis, according to Ferguson and Lavalette (2013), began over two decades ago in the late 1980s, with the Conservative government's decision to open social care provision to market forces and non-state operators, and has continued until the present. The transfer of large sections of publicly funded care over to the private sector was accompanied by the promise of choice for consumers to purchase high quality support services from a variety of providers operating within a mixed economy of care. However, as Ferguson and Lavalette (2013) argue, markets have failed to deliver on both choice and quality aspects as social care, and in particular residential care, became dominated by a small number of large multinational corporations, who primarily focused on profit maximisation rather than welfare of their residents.

The failure of the market and the state to respond effectively to the growing social care crisis has triggered an interest in other players, such as voluntary and community organisations (Milligan, 2007). As part of the shift towards a pluralised social economy, voluntarism gained a more prominent place in policy discourses, with politicians and policy makers calling for a greater role for the 'Third Sector' organisations in health and care service delivery (Fyfe and Milligan, 2003; Skinner and Power, 2011). As highlighted by Kendall and Knapp (1996), historically the UK voluntary sector has had a long-standing involvement in the delivery of health and social care services, and, according to Milligan, the importance of the sector has increased even further in recent decades, as it was 'assigned an elevated role' not only in service delivery but also in the policy design (Milligan, 2001: 5). The portrayal of voluntarism in political and academic discourses as a 'panacea' to social and political problems' (Fyfe and Milligan, 2003: 397) has resulted in the assumptions that voluntary sector and volunteers are able and willing to address the welfare needs of vulnerable populations, in particular – the health and care needs of the growing ageing population (Skinner and Power, 2011). The increasingly more prominent role of the voluntary sector in welfare provision has been described as a ‘voluntary’ or ‘community’ turn (Macmillan and Townsend, 2006: 15).

The ‘voluntary’ turn, according to some commentators, can be viewed optimistically as a grass-roots approach to health and social care working in the areas of need not reached by formal care provision, or pessimistically as a drive by governments to plug the gaps in provision left by budget cuts (Hanlon, Halseth and Ostry, 2011). Differing views on how to define and classify the voluntary sector and the act of volunteering itself are also a recurring topic within debates about voluntarism (Kendall and Knapp, 2005; Milligan and Conradson, 2006; Power, 2010). For example, having described the sector as a ‘loose and baggy monster’, Kendall and Knapp (2005: 65) offer a number of taxonomies of voluntary organisations related to the purposes for which the description may be required. The authors emphasise that there is ‘no single correct definition to be used in all circumstances’, and that each classification has its merits and drawbacks (Kendall and Knapp, 1996: 17).

The first set of categories proposed by the scholars is based on the primary function of the organisation such as direct service provision, mutual aid, including self-help, campaigning and lobbying, advocacy, and general voluntary sector coordination (Kendall and Knapp, 2005). Another set of categories focuses on the organisation’s ‘arrangements for control’ and ‘method of resourcing’, including funding and human resources (Kendal and Knapp, 2005: 67). Here the authors distinguish between democratic bodies, whose trustees are elected and oligarchic structures with appointed governors; these are further subdivided into organisations primarily run by volunteers and those mostly relying on paid staff. Yet another proposed taxonomy of voluntary organisations concerns their norms and values, which, as some commentators suggest, are distinct from values held by the private and governmental sectors, reflecting the norms and beliefs of their founders (Jeavons, 1992). Kendall and Knapp (2005), however, argue that it would be problematic to make a clear distinction between the sectors based on values, as motivations may vary within organisations, and because the voluntary, private and government service providers are ‘operating within a mixed and increasingly blurred economy’ (Kendall and Knapp, 2005: 72).

The boundaries between the governmental and voluntary sectors are even less clearly defined when the latter’s engagement in diverse activities or ‘industries’ is examined. As a major provider of social services to people with disabilities, children, older people and other groups classed as vulnerable, the sector in general and its larger ‘brand name’ charities in particular, have ‘intimate links with local and central government’ which finances social service delivery through grants and contracts (Kendall and Knapp, 2005: 74). To conclude the discussion of the diverse categorisations of voluntary sector organisations, the authors propose five core criteria based on structural and operational aspects of voluntary entities, namely, the body should be formally organised, self-governing in structure and independent of government, not profit distributing and non-business, and, finally, have a degree of voluntary involvement from citizens in its service delivery (Kendall and Knapp, 2005). Similar core criteria can be found in definitions employed by other scholars. For example, Power’s (2010) description of the voluntary and community sector includes the self-governing, non-business and the voluntarism categories. The scholar echoes Kendall and Knapp’s (2005) point that organisations employing paid staff and receiving statutory income can still be classed as voluntary as long as they are established and governed by volunteer boards (Power, 2010).

While having discussed methods of financial resourcing as one of the ways of categorising voluntary organisations, Kendall and Knapp (2005) have not included it into their structural operational definition of the sector, which they have used for the purposes of a cross-national comparison. Other scholars, however, employed the ‘resources’ criterion as a means to analyse and make sense of the ‘chaotic’ nature of the voluntary sector (Milligan, 2001: 114). In her study of the impact of changes to care provision characterised by the shift in the statutory provision to the informal sector, including voluntary and private entities, Milligan (2001) has developed a typology of voluntary organisations based on sources of their funding and on mechanisms through which funding is accessed. For the purposes of analysis the scholar has defined three types of organisations, namely those funded through contractual and service agreements; bodies funded through central and local grants; and those whose resources are secured through independent fund-raising activities, donations and legacies. Milligan (2001: 119)points out that most organisations in the study indicated that their income came from mixed sources, thus it was necessary to group them using the criterion of the ‘predominance’ of a particular source which, as analysis revealed, was the statutory sector. Such funding arrangements, have a significant impact on how voluntary organisations in different localities ‘translate’ the central government’s social care priorities and directions, and ‘mediate’ and implement them at the local level (Milligan, 2001: 119).

2.1.10. The relationship between formal and informal sectors: questions for geographers

The public sector’s offloading of health and social care services on to private and voluntary bodies has had a major impact on the actants within what Milligan terms ‘locally-embedded networks of care’ (2001: 209). In addition to spatial changes characterised by the shift of the locus of care from larger institutions to the community setting (Milligan, 2001), the emerging ‘welfare pluralism’ has introduced another layer of complexity into the interrelationships between the state and the private and voluntary sectors (Fyfe and Milligan, 2003: 401). Before major transformations in welfare provision took place, geographers drew attention to the complex relationship between the voluntary sector and the state. Wolch’s ‘shadow state’ thesis, for example, focused on the voluntary sector’s ability to penetrate everyday private lives of citizens with little accountability, as it operates ‘outside traditional democratic politics’ under the control of the state (Wolch, 1989: 201).

Certainly, the sector’s continuing dependence on state contracts and grants only reinforces state control making opposition to its policies ‘not a viable option’ for many voluntary providers (Fyfe and Milligan, 2003: 401). Having recently revisited the ‘shadow state’ thesis and analysed the concept through the lens of the devolution of state responsibilities, Wolch (2006) has commented on the fragmentation of voluntary landscapes, where larger well-established organisations are expanding with the state support while smaller grass roots entities are lost, as they find themselves unable to adapt to the new initiatives. This view is echoed by Milligan and Conradson (2006) who point to the dilemma faced by voluntary organisations of accepting state funding at the expense of their independence or even survival. While Wolch's 'shadow state' thesis is still relevant to the analysis of the state – voluntary sector relationships within the current economic context, in which civil society organisations have become central players in welfare governance and provision, its scope does not extend to newly emerging joint ventures between private and voluntary bodies (Fyfe and Milligan, 2003). Fyfe and Milligan (2003) have called on geographers to examine the new political and economic landscapes in all their complexity, including the growing involvement of the private sector in welfare provision and the relationships between the voluntary, private and state sectors at global and local scales (Fyfe and Milligan, 2003: 410).

The importance of scale and place to the geographical analysis of voluntarism has been highlighted by a number of geographers (Wolch, 2006; Milligan, 2007; Skinner and Fleuret, 2011; Skinner and Power, 2011). It has been argued that the extent of to which voluntary activity is developed in different places does not always reflect the need to which the activity is supposed to respond. Although the state approaches undoubtedly have a significant influence on the sector's development, often the variations in the geographies of voluntarism can be explained by other factors (Milligan, 2007). These may include the prosperity of a certain locality (Gorsky and Mohan, 2001), differences in culture, socio-economic circumstances and local history of donations and philanthropy, the presence of 'champions' of the cause instrumental in securing resources to support it and so on (Milligan, 2007: 191).

Calling for further theorisation of connections between voluntarism, health and place, Skinner and Power (2011) have argued that place has a critical impact on the development of voluntary activity. Voluntary activity is embedded in place and its specific cultural, historical and political characteristics are influenced by place. The introduction of scale into geographical analysis of the relationships between the voluntary, private and public sectors will enable researchers to understand how social care policy, conceived at the national level, is translated and mediated at 'meso and micro environments' where the former is equated to the local governance level, and the latter – to that of an individual (Milligan, 2001: 28). A number of commentators are in agreement that the gap in the study of the interdependence and interrelationships between the voluntary, public and private sectors at various scales should be addressed through place-specific studies focused on daily practices of voluntary activity and its outcomes at the micro-level (Wolch, 2006; Fyfe and Milligan, 2003; Skinner and Power, 2011). Approaching voluntary activity through the focus on its practice ‘on a contextually specific basis’, according to Hanlon, Halseth and Ostry, (2011:42) will help to elucidate its rich variety. By exploring local experiences of voluntary sector organisations, geographers will be able to map the voluntary sector’s response to the restructuring of welfare provision coupled with the challenges of ageing population (Skinner and Fleuret, 2011).

2.2. Ageing in place

2.2.1. The intersectional approach to the study of the interrelationship between ageing and place

In their review of theoretical developments within the field of geographical research on ageing Harper and Laws (1995) commented on the major shift in epistemological approaches within human geography. Positivist and even humanist schools of thought, they argued, could no longer offer new challenges to philosophical and methodological debates taking place within social sciences in general, and human geography in particular. However, although theoretical influences of postmodernist and feminist epistemologies had made a significant impact on human geography as a discipline overall, they were at the time underutilised within the geography of ageing (Harper and Laws, 1995). The authors drew on the concept of ‘postmodern lifecourses’ which rejects the linear modernist description of the major life milestones – from youth, to adulthood, to old age, and instead propose ‘a multiplicity’ of paths (1995: 213). The authors maintained that these multiple postmodern identities are inextricably linked to and shaped by places, as well as shaping places in their turn: ‘Places, as much as people, have socially constructed identities and the identities of places and people feed upon each other’ (1995: 214). To illustrate this idea, Harper and Laws use an example of retirement enclaves in Arizona, where identity construction is manipulated through images of ‘youthful activities’ and lifestyles offered for consumption to the retirees (1995: 214).

The intersection between age and place is further discussed by McHugh (2003) who illuminates how both variables impact each other using the example of retirement communities in Arizona’s Sun Belt, mentioned previously in Harper and Laws’ overview (1995). Adopting the ‘spatiality perspective’ which views place and society as ‘mutually constitutive’, McHugh analyses images and narratives presented by marketing agencies in Arizona to potential residents, who are, in the majority, retired (2003: 166). The images invariably picture these enclaves as places of ‘successful ageing’, holding a ‘secret to longevity for retirees’, where youthful lifestyles are achieved through intensive consumption of neatly packaged geographical features combined with challenging physical activities, such as cycling in the wilderness of the Grand Canyon or hiking in the desert (McHugh, 2003: 166). He argues that through the use of skillfully crafted positive imagery of an active later life emplaced in a geographically diverse, exciting location, the marketing industry has merely replicated the dichotomous view of the older age already deeply rooted within the society – that of a ‘good’ old age, characterised by independence, good health and an active healthy lifestyle, and a ‘bad’ old age mired in dependency, illness and frailty. These conflicting images of the later life are brought together under what McHugh terms ‘bipolar ageism’, where the positive side is as equally harmful as negative, as it normalises a utopian and unachievable view of an ageless senior (2003: 179). Although he arrives at a somewhat pessimistic conclusion doubting whether an ageism free society is at all possible, McHugh, nevertheless, highlights some positive sides to living in a retirement enclave, in particular the opportunity to live in a place ‘where everybody is old so nobody is old’ (2003:181).

The view that place and age impact each other is echoed by Blaikie (2005) in his exploration of the interplay between imagined landscapes and identity in later life. Using British coastal towns as an example, Blaikie (2005) traces the transformation of these places from imagined idylls of the Victorian times affordable only to affluent middle class retirees, to the real places of today where populations of people aged over sixty sometimes outnumber other age groups. This, according to Blaikie, demonstrates that people can shape and reconstruct places ‘in their own desired image’ (2005: 168). Blaikie’s examination of Sun City type retirement enclaves echoes McHugh’s (2003) findings revealing that to some migrant retirees these places offer a communal life among people with similar values and backgrounds. Thus UK coastal towns and Arizona’s Sun Belt villages have become places of escape from the ageist society, ‘a space to withdraw from the mainstream’ (Blaikie 2005: 169).

Blaikie (2005) extends his analysis of the interrelations between places and older people’s identities by considering the retirees’ class and wealth. He emphasizes that only those who can afford it are able to engage in what he describes as a ‘privileged retreatism’, while the majority have to live their later lives fully exposed to the society’s ageism (Blaikie 2005: 169). The affluent are therefore able to live their dream of the active and fulfilling ‘good’ old age, emplaced within specially designed retreats, whereas the ‘bad’ old age is reserved for the poor. This dichotomous view of older age as ‘good’ and ‘bad’ is traced by Blaikie (2005) to the Protestant work ethic in which self-reliance, independence and hard work were considered virtues and the ill health was viewed as a punishment for a life of sin. He argues that this ethic with its clearly outlined moral anchors is what makes retirement communities appealing to many older people, who may be searching for a ‘moral community’ in age segregated places (Blaikie 2005 : 170).

The intersection between place and age is comprehensively explicated in Pain, Mowl and Talbot’s (1999) research on the use of leisure spaces by older people in two areas of Newcastle upon Tyne. The authors’ central argument is that socially constructed age identities can be challenged, resisted and negotiated through the use or non-use of certain places (Pain et al, 2000). They point out that ageism should be viewed as a complex interplay of power relations, not simply directed from one group towards another, but bound up with social identifiers other than age, such as class, gender, ability and so on. They go on to say that ‘ageist practices which label, include, and exclude may be practiced by and between older people’ (Pain et al, 2000: 379). Through empirical data collected via interviews and observations of older people from a middle class and a working class areas of Newcastle, the researchers gained an understanding of how age, gender, class and ability of the participants intersected with their ideas about what leisure spaces were desirable and fitting to their social status as well as that of others. The research revealed that there was a clear hierarchy between places: working class men did not use ‘middle class’ clubs where educational talks and lectures were among activities on offer; similarly, middle class retired professional men did not drink at ‘working’ class establishments, which they believed were frequented by people ‘whose brains have atrophied’ due to the lack of intellectual stimulation (Pain et al, 2000: 384). It transpired that some middle class people considered working class leisure facilities as places for old people, aged both physically and mentally. They associated activities such as playing bingo with mental decline and frailty (Pain et al, 2000). By distancing themselves from what they perceived as old people’s places and lifestyles, the middle class people created their own strategies of resistance to being labelled as old by the society. The research revealed that class was one of the significant and influential variables, along with gender and ability, in the process of older identity construction. The intersection of these components with the spatial element has produced a complex picture of a spatially constructed older age (Pain et al, 2000).

The adoption of the intersectional approach to the study of age in geography has helped researchers to identify and explore the ‘spatial practices’ of older generations, as demonstrated by the examples cited above (Hopkins and Pain, 2007: 287). There is still, however, little research into the intersection and interaction between age, gender, class, ability and place, according to Hopkins and Pain (2007). The authors call on geographers to continue emphasising the importance of place to the construction of complex identities of later life, as well as to be attentive to ‘who else older, middle-aged or young people are’ (Hopkins and Pain, 2007: 290).

2.2.2. Beyond medicine

The geographical study of older age has taken place within the sub-discipline of medical geography (Kearns and Andrews, 2005; Parr, 2002). The shift from research predominantly focused on disease and health service to an interest in health, well-being and social models of health and care occurred in the 1990s, informed by the critical perspectives brought into the discipline by feminism and qualitative methodological approaches. (Kearns, 1993; Parr, 2002; Kearns and Andrews, 2005). Research directions of the ‘post-medical geography’ that emerged focused on ‘the person, their body an and their lived situations rather than dwelling on disembodied diseases (Kearns and Andrews, 2005: 14). The ‘cultural turn’ informed by postmodernism, post-structuralism and social constructivist thinking also influenced health geography, shaping theorisations of place. Place began to matter and its influence on health became central to geographical research into health (Kearns and Moon, 2002).

Informed by this cultural turn geographers of older age began to focus on the issues of older people has incorporated the geographical concepts of place and space as elements pivotal to the ‘constitution of social relations’, shaping lives and experiences of older adults as well as being shaped by them (Andrews et al, 2007: 162). The work on the ‘place-embedded experiences of ageing, health, care and wellbeing’ (Skinner et al, 2014: 3) falls within four broad areas arranged in an ‘outward scale from the person’ by Kearns and Andrews (2005: 15) – the body, the home, residential care settings and landscapes of ageing. While some scholars theorise ‘landscapes of ageing’ as defined physical localities, others see them as places where history, social structure and relations and built environment connect and interact (Kearns and Moon, 2002). This study is based on the understanding of landscapes of ageing as a convergence of the ‘embodied, emplaced and relational’ aspects of ageing (Schwanen et al, 2012: 1292) with place that is experienced and shaped by older people (Kearns, 1993).

2.2.3. The meaning of home to older people

The interrelationships between place and older age are multi-faceted and are largely defined by how society views ageing. For example, negative representations of older age as a state of physical deterioration and mental decline have shaped the image of residential and nursing homes as places of ‘concealment and disengagement of the body from society' (Kearns and Andrews, 2005: 15). Home, on the other hand, is seen in a positive light as a place where independence, ability and identity are maintained. Negative images of older age and places, according to Kearns and Andrews (2005), are over-represented in public debate. Kearns and Andrews (2005) point out that although only a relatively small number of older people develop dementia, nursing homes specialising in care for people living with dementia often receive more attention than living spaces of the majority without the condition. Echoing the point that images of places affect how relationship between places and older people develop, Phillips (2007) highlights how some locations, such as care homes, are stigmatised while others, such as home, are sentimentalised.

Home is particularly important for older people as some of them may spend most of their time within its restricted space because of diminished mobility or other health-related issues. As Williams (2002) has suggested, it is crucial for geographers to develop a critical reading of home as place, its meaning and impact on older people's perception of independent living, identity and well-being (Williams, 2002). In the course of the ageing process, space and place are redefined and renegotiated, and new meanings of domestic space are constructed (Cristoforetti et al, 2011). An emotional attachment to place, described by Cristoforetti et al (2011) as 'a set of feelings about a geographic location that emotionally bind a person to that place' (2011: 225) is especially evident in the way older people relate to home which for many represents independence and continued competence (Williams, 2002; Christoforetti et al, 2011). The attachment to place, as demonstrated by Wiles et al (2011) in a study of the concept of 'ageing in place' with two communities in New Zealand, extends from home out to neighbourhoods and communities. Besides emotional attachment, the study revealed functional attachment represented by housing, transportation and outdoor spaces, and symbolic attachment reflected in the sense of meaning, security and familiarity in relation to homes as well as communities (Wiles et al, 2011). While ageing in place was linked to independence and autonomy, Wiles et al (2011) emphasised that its meaning also had 'pragmatic implications beyond internal feel good aspects' such as knowing the location of surgeries and supermarkets and being greeted by neighbours (Wiles et al, 2011: 357). Highlighting the concept of place as a process operating at different scales, Wiles et al (2015) argue that ways people age in place are diverse and individual, shaped by the multitude of connections to the neighbourhood, and community, as well as different interpretations of the meaning of autonomy and home.

Examining the influence of neighbourhoods and networks on older people's experience of ageing in place, Gardner (2011) approaches neighbourhood as a process central to the construction of identity and social relations. This perspective, allowed to draw a theoretical link between the physical environment and the social milieu at the neighbourhood level, which helped to elucidate the relationship between ageing and place (Gardner, 2011). One of the study's findings highlighted the positive impact of 'non-kin relationships' embedded within the broader social network on the well-being of older people (Gardner, 2011: 268). The category termed 'others' comprised neighbours, people employed by local businesses and transport companies, and strangers encountered by older people, with whom natural relationships and interactions developed. Gardner (2011) concludes that these 'others' formed a key part of the social network of older residents. The author maintains that interactions with non-family 'others' will play an increasingly significant role in the lives and well-being of older people in future in the context of the changing structure and proximity of families, expanding life expectancy and an increasing use of technologies to enable independent living. The findings of Gardner's (2011) study are particularly relevant to this research project as it examines the role of non-kin befrienders in the provision of informal care and companionship to people living with dementia.

2.2.4. Problematization and (bio)medicalization of older age

Current demographic changes, particularly the ageing of population in Europe, the United States, Canada and Japan among others, have moved the concerns surrounding age relations, health and care to the centre of debates within policy making and research on ageing (Joyce and Loe, 2010). Anxieties caused by the increase in numbers of older people are reflected in the emotive language sometimes used to describe the phenomenon, where it is referred to as the 'graying' (Joyce and Loe, 2010: 2), a 'social policy timebomb' (Kenner, 2008: 259) and even a 'silver tsunami' (Mort el al, 2013: 801). Against the backdrop of ageism older age and older people themselves are framed as problematic and abnormal, ageing bodies and minds are pathologised and positioned as a concern of biomedical experts (Estes and Binney, 1989; Kenner, 2008; Joyce and Loe, 2010).

Such problematization of older age, as Katz (1996) argues, has its origins in 'the discourse of alarmist demography' of the late nineteenth and earlier twentieth centuries, which anxiously predicted the emergence a rapidly increasing ageing population characterised by 'poverty, neediness and unproductivity' (1996: 127). This discourse developed alongside progress in medical sciences and practices which began to describe the aged body as different, separated by disease from other age groups. While premodern medicine, according to Katz (1996), separated illness from health and life from death, 'the medical gaze' of the nineteenth century 'abandoned these distinctions and replaced them with a single grid of perception framed by pathology and normality' (1996: 43). This binary logic of 'the normal and the pathological' extended out from the confines of medical science and permeated the governance of social relations, defining the concepts of norm and normality and setting moral and statistical standards (1996: 43). Katz (1996) maintains that these practices were not necessarily wholly negative, as rather than negating the aged body, they made its vulnerabilities more salient and accessible to scientific scrutiny, and brought about such social assistance measures as insurance, retirement and pensions. Thus Katz (1996) disagrees with the popular criticism of medicine which charges it with the repression of human nature, instead the human nature is reproduced 'through specific discursive practices' which may have negative or positive implications (1996: 27).

Katz's (1996) conclusions are echoed by Rose (2007) who calls for a reconsideration of the use of the term 'medicalisation' as an explanation, description, and a critique within social the analysis of medicine. He argues that defining medicalisation as 'the extension of medical authority beyond a legitimate boundary' (Rose, 2007: 701) is unhelpful because the definition presents medicine, medical knowledge and medical practices as a single entity impervious to the impacts of locales, technologies, age, class, race, nationality, and sex of medical professionals and patients. Rose's (2007) analysis of the effects of medicalisation on human beings focuses on three dimensions – medical forms of life, medical meaning and medical expertise. Medicine, he maintains, has modified the contemporary human life form – ranging from our appearance to longevity. Rose (2007) illustrates this through the example of vaccination – 'hybridising human beings with dead or deactivated bacteria', which has transformed 'human sociality, saved millions of lives and contributed to the growth of the population', thus helping make us 'the kinds of living creatures that we have become at the start of the 21st century' (2007: 701).

Rose's (2007) description of 'hybridism' achieved through medicine echoes Haraway's (1991) idea that advances in scientific culture in general, and medicine in particular, have ruptured the boundaries between human and non-human resulting the creation of hybrids between organisms, and in effect made all human beings a mixture of 'ourselves and other organic creatures' (1991: 22). Further discussing the concept of medical expertise Rose (2007) critiques the belief that medicine's authority should be limited to the management of disease or pathology. Through their involvement in such social issues as disease mapping, sewerage design and town planning since the early 19th century medical professionals became, Rose argues, 'first social scientists', engaged with not only 'individual' but also 'collective bodies' (Rose, 2007: 701). Today this expertise extends to 'the management of life itself' – from new reproductive technologies, to childbirth, death, stress, dementia and old age (Rose, 2007: 701). In the final part of his argument Rose emphasises that since 'medicine has made us thoroughly artificial', and we are leading 'medical forms of life', medicalisation in itself should not be viewed as 'the conclusion of an analysis', but rather as a neutral term, an opening for a critical evaluation of the ways in which medical science and practices shape human lives (2007: 702).

Some scholars go further in their calls to reassess the impact of medicalisation, particularly on the lives and health of older people. For example, Ebrahim (2002) argues that the shift to de-medicalisation of elderly people's health problems in the last decade has resulted in the 'warehousing' of the elderly in nursing homes with the ensuing neglect for their health needs (Ebrahim, 2002: 862). Heath (2000) warns that redefining medical care as social care may lead to the distancing of older people from specialist medical services, the loss of dignity among those who can no longer perform personal care independently, and the overall ‘dereliction of duty’ towards the frailest elderly (2000: 1422). Both scholars, while acknowledging the dangers of excessive medicalisation, are nevertheless critical of policy makers’ rationale for de-medicalisation, citing political ideology, cost saving and an unjust rationing of health care resources as some of the possible pushes (Heath, 2000; Ebrahim, 2002). Ebrahim (2002) champions the encouragement of medicalisation of old age, which she argues will lead to better access to necessary treatments, reductions in mortality and disability, and improvements in the quality of life for older people. Neglecting older people’s medical problems and redefining them as social, on the other hand, should be opposed.

Drawing from the medicalisation concept Clarke et al describe how the intensification of medicalisation engendered by ‘the problems of late modernity or post-modernity’ has resulted in the biomedicalisation of life, its transformation from ‘inside out’ made possible by the scientific progress (2003: 164; 176). Biomedicalisation is defined by the authors an ‘increasingly complex, multisited, multidirectional process of medicalisation’ with its roots in the rapid development of ‘technoscientific knowledge’ and innovations such as molecular biology, genomization, transplant medicine, bioengineering, and telehealth among others (2003: 162). While medicalisation is theorised as a broadening of medical control from illness on to other areas of people’s lives covering such spheres as substance abuse, reproduction and sexuality, biomedicalisation, according to Clarke et al, reaches deep into and alters our ‘internal nature’ and ‘biological processes’ of life (2003: 164).

Using the example of Western medicine, the authors trace the development of medicalisation through time, illuminating main milestones of its advance – from ‘professionalization and specialization’ of medicine and its institutions in the late nineteenth century, to the extension of its jurisdiction to treat conditions previously classed as criminal and deviant, described as a shift ‘from badness to sickness’, to the inclusion of ‘all new phenomena deemed medical problems’ such as premenstrual syndrome and attention deficit hyperactivity disorder among others (Clarke et al, 2003: 163; 164). The transformation of medicalisation into biomedicalisation, the authors argue, took place in the 1980 brought about by the technoscientific revolution. The advance of medical knowledge has led to the possibility of the ‘big science’ and ‘big technology’ to ‘sit on your desk, reside in a pillbox or inside your body’, while at the same time widening the influence of medicalisation to include, in addition to illness, a range of the so called ‘undesirable or stigmatizable’ conditions such as obesity and unattractiveness with cures such as diet medication and cosmetic surgery readily available (Clarke et al, 2003: 164).

Clarke et als’ (2003: 184) assertion that ‘we are awash at sea of biomedicalising discourses’ echoes Katz’ (1996) conclusions about the significant impact of medical discourse on the reproduction of human nature. Among the discourses delineated and unwrapped by Clarke et al (2003) are those relating to how the transformation of bodies and identities by the process of biomedicalisation has resulted in the creation of new individual and collective technoscientific identities (Clarke et al, 2003). Biomedicalised health, they argue, becomes a commodity, and ‘a biomedically (re)engineered body becomes a prized possession’ (Clarke et al, 2003: 171). Thus, ‘desires for transformed bodies and selves’ justify and even demand more and more biomedical manipulation, routinizing interventions previously considered necessary only in the treatment of pathology (Clarke et al, 2003: 181). Addressing these aspirations in an exploration of the effects of biomedicalisation on later life, Kaufman et al (2004) describe the pursuit of ‘ageless’ bodies through the application of biomedical procedures as a yearning ‘to be better than well’ (2004: 736), while the refusal to seek life extending treatments is increasingly viewed as ‘a sign of deviance’ (Joyce and Mamo, 2006: 104).

Taking trends relating to the biomedical model of ageing theorised by Estes and Binney (1989) as the starting point, the Kaufman et al (2004) map current new forms of biomedicalisation and explicate their influence on the ‘ethics of normalcy’ in medical care for the elderly (2004: 731). The study focused on three types of medical procedures that the researchers describe as already routine or becoming so for the oldest adults– cardiac procedures, kidney dialysis and kidney transplant (Kaufman et al, 2004). The research has revealed an increase in the use of the interventions for ever-older ages, with octogenarians comprising the fastest growing group of surgical patients in the United States (Kaufman et al, 2004). Developments in the biomedical science, the authors argue, have transformed our expectations about what is possible and achievable through biomedical interventions, opening the body to an ‘unlimited manipulation at any age’ and giving health professions the power over ‘the management and maximisation of life itself’ (2004: 732).

The biomedical construction of ageing as a pathology, theorised by Estes and Binney (1989), has endured and is evident in today’s medicine which is still considered the only right tool for managing problems associated with the process. Kaufman et al (2004: 732) argue that the availability of biomedical interventions coupled with the discourse of life extension, dominant across the medical science and practices, have produced a new ‘socioethical landscape’ characterised by ‘the difficulty or impossibility of saying ‘no’ to life-extending procedures’. This is manifested through the ‘greying’ of the population receiving kidney dialysis, the dramatic increase in kidney transplants in people aged over 70, and cardiac bypass surgeries for nonagenarians becoming more usual (Kaufman et al, 2004). The authors emphasise that they do not take an ideological stand on when or to what extent such procedures should be available to older people, rather by exploring these changes in medical care they describe how the new ethic of care engendered by the routinisation of complex biomedical interventions and expectations ‘for cure, restoration, enhancement, and quality of life’ has altered our perception of ‘what can be done, medically or surgically, for older persons’ (Kaufman et al, 2004: 732; 734).

Kaufman et al (2004: 734) point to an interesting turn in biomedicalisation of old age where, on the one hand, the ageing process is still seen as deterioration and decline, while on the other hand, with the availability of life-extending medical procedures age is ‘frequently dis-appeared’, an ‘appropriate time to die’ moves up and dying at the age of 75 is perceived as wrong and unnatural The ability of biomedicine to achieve ‘the extension of life at all costs’ (Estes and Binney, 1989: 595) makes it difficult for patients and families to decline medical intervention. For families in particular, the choice to accept treatment may be seen as an expression of care and love, and so ‘technological imperative becomes a moral imperative’ (Kaufman et al, 2004: 735). Biomedicalisation of ageing, as demonstrated by Kaufman et al (2004: 736), is transforming the bodies of older people, who undergo increasingly routinized and therefore expected and desired medical procedures to achieve survival, restoration and even ‘slowing of the ageing process’. It also creates new technoscientific identities defined by Clarke et al as not new in themselves but social identities refashioned by ‘technoscientific applications’ and expressed in new ways (2003: 182). For example, through the application of a variety of biomedical techniques, such as joint replacements, memory enhancement, drugs for impotence and so on, the middle age is stretched into later life and we are given the opportunity to grow old without ageing (Kaufman et al, 2004).

2.2.5. Biomedicalisation of dementia

The biomedical model of dementia still provides a powerful framework for the study and management of the condition both within literature and practice (Lyman, 1989; Bond, 1992; Downs, 2000). Lyman describes the gradual development of the model, tracing its origins to the early 19th century when ‘medicalisation of deviance’ in general, and ‘medicalisation of madness’ in particular, took shape in the context of the growth of medical science and the extension of its influence over personal and social problems (Lyman, 1989: 598). While in the Middle Ages ‘madness’ covered a range of conditions, including depression and dementia and was considered a retribution for one’s sins within the predominant ‘theological model’, in the early 19th century physical punishments were ‘substituted by moral restraints’ proscribing a ‘moral treatment’ consisting of a strict daily routine and work therapy (Lyman, 1989: 598).

Adopting a ‘historical-social constructivist approach’ within which deviance designation reflects broader socio-political shifts, Conrad and Schneider (1980: 27) develop a concept of medicalisation of deviance rooted in three paradigms - ‘deviance as sin, deviance as crime, and deviance as sickness’. Debates around what behaviours should be classed as deviant, according to the authors, have a political dimension, as they establish ‘the appropriate agent of social control for such deviance’ who acquires the power to enforce categories of deviance on other groups in society (1980: 25). Thus, the theological view of deviance as sin was maintained by a community of religious leaders, while currently in our ‘scientifically oriented’ post-industrial world deviance is designated increasingly as a medical problem, reflecting the influence and acceptance of science and medical authority (Conrad and Schneider, 1980: 28). The shift from designating deviance as crime to a medical conception, ‘from badness to sickness’, described by Conrad and Schneider (1980: 34) as a ‘humanitarian trend’ because of a ‘therapeutic’ rather that ‘punitive’ social response, resulted in an expansion of medicine’s capacity for social control, with more and more behaviours previously seen as criminal becoming medicalised. In addition to mental illness that was medicalised to a great extent, categories of sickness were gradually applied to alcoholism, drug addiction, hyperactive children, obesity, violence and so on. The more complete medicalisation of mental illness, argue the Conrad and Schneider (1980), was the result of ‘a few recurrent themes in the history of medical concept of madness’, those of optimistic searches for the cure followed by the failure to produce it, giving rise to the belief that the causes of madness were located within physiology or the so called ‘degeneration hypothesis’ (Conrad and Schneider, 1980: 72). This in turn led to a further intensification in the medical model of mental illness and an increase in the interest in technologies of cure, including medication, genetics and behaviour modification therapies (Conrad and Schneider, 1980).

The view of dementia as ‘senility’, a part of normal ageing, rooted in the ‘degeneration hypothesis’ was challenged relatively recently, with the emergence of Alzheimer’s disease as ‘an illness category and policy issue’ in the 1980s (Lyman, 1989: 597). Lyman (1989) attributes the increase in the policy makers’ and researchers’ attention to the illness to the view of dementia as a costly epidemic spreading among the rising numbers of the oldest old. Although dementia is only one of many conditions of old age, some of which are more prevalent, it was given the status of ‘the disease of the century’ and funds for research to find cure saw a significant increase (Lyman, 1989). The biomedical science claimed ownership of the disease and described it as pathological and individual, an abnormal condition of cognitive impairment, dysfunction and mental disorder with causes attributed to ‘progressive deterioration of brain regions that control memory, language and other intellectual functioning’ (Lyman, 1989: 599). Biomedical assessments for diagnosis and management strategies were developed and widely accepted. These developments, according to Lyman (1989), resulted in a number of positive outcomes for people with dementia and carers: firstly the view of senility as an inevitable part of old age was re-examined and refuted; secondly, the model offered a clear overview of the condition with a predictable trajectory, having a beginning, middle and end, and thus introduced a degree of order and control into stressful lives of family carers; thirdly, it energised and introduced a sense of urgency into research and policy. However, the biomedical approach to dementia, argues Lyman, also has significant limitations: firstly, in its description of experience of the condition and its progression it fails to consider such social factors as the context within which care is provided, 'the power relationship of caregiving and dependency' and stress experienced by carers and people with dementia; secondly, the view of the progression of the disease as 'stagelike' may result in an 'oversimplified prognosis' and bring about expectations of the inevitable decline and a decrease in opportunities to maintain 'meaningful activity' (1989: 599).

The 'disease typification' and overgeneralisation about the behaviour of the person diagnosed with dementia may alter the way the person is treated by others around them, leading to a situation where carers begin to 'see impairment everywhere' (Lyman, 1989: 603). Being labelled with certain characteristics, according to Bond (1992), is likely to have an impact on the individual's perception of self and his or her behaviour towards others. Drawing on the concept of 'secondary deviance', a process whereby the person labelled as 'deviant' begins to 'act the role which the new label implies', Bond argues that the label of 'senility' applied to an elderly person may trigger changes in behaviour (1992: 399). Being diagnosed with an incurable chronic illness often leads to a sharp decrease in self-esteem, social isolation and 'negative expectations of others' (Lyman, 1989: 600). These changes in behaviour, coupled with the effect of being treated as 'demented' by others, may be difficult to distinguish from the symptoms of the pathological condition relying on the biomedical model alone; this can be rectified by framing the illness within 'a socio-cultural as well as a biomedical definition'(Lyman,1989:600).

Another aspect of medicalisation - the individualisation of deviant behaviour, described as a focus on the individual rather than the social structure in the search for solutions for complex social problems, has a number of implications for people with dementia and carers (Bond, 1992). As the diagnosis and the treatment of the illness are the only concerns of the biomedical model of dementia, the context of the social system in which these take place becomes irrelevant, according to Bond (1992). Similarly, the characteristics of the social structure within which the caring relationship is performed are ignored and while the carer's personality is put in the spotlight (Bond, 1992). While the individualised focus on the course of the disease, treatment, resistance and so on may be beneficial in the context of a 'doctor-patient' relationship, the neglect of 'larger social and environmental factors' and the reductionist view of the illness as an isolated problem may result in a 'blame the victim mentality' and 'social control' through medical management, such as medication and institutionalisation (Estes and Binney, 1989: 588). Decisions about diagnosis and care, according to Estes and Binney (1989) are made in the environment of the structural power imbalance present in the relations between physician and patient within the wider context of medicalisation of old age. The powerful role of medicine 'as an institution' of social control and doctors as its 'agents' is highlighted by Bond who argues that the social status of being ill or well, 'certified' as having dementia or not is determined by a psychiatrist 'independent of the beliefs of caregivers or an individual's own beliefs' (1992: 400).

Debates about individualisation of behaviour are situated within the wider theoretical concept of the 'individualisation of life (including ageing) in late modernity' (Baars, Dohmen and Grenier, 2013: 2). Referring to social critiques such as critical gerontology and structural analysis the authors counter the assertion that older people's social problems are caused by 'inevitable results of senescing', 'irresponsible actions' of those affected, 'a mere chance' or 'unfortunate decisions' (Baars, Dohmen and Grenier, 2013: 2). Individuals, argue Baars et al (2013: 2) should not be held responsible or blamed for the effects of such major problems as poor housing, insufficient income and bad healthcare, as these issues are 'constructed through the operation of economic and political forces'. The individualised view of healthcare, for example, positions health as 'an individual goal', making it 'the individual moral responsibility to be and remain healthy' (Clarke et al, 2003: 171). In the context of biomedicalisation health becomes 'something to work toward' through the exercise of self-discipline as well as the use of 'commodities, services, procedures and technologies' (Clarke et al, 2003: 172).

2.2.6. Perspectives of dementia: Personhood and citizenship

In order to counter the ‘near-sighted’ biomedical view of dementia, according to Lyman, social gerontology should examine social forces involved in the construction of the illness, including ‘cultural definitions’ of dementia, ‘the socioenvironmental context’ in which care is provided and received, and ‘the dynamics of the caregiving relationship’ (1989: 604). Lyman (1989) proposes to adopt ‘the sociogenic’ perspective in dementia research and practice, the model that describes all human experience as action and interaction taking place in ‘socially-structured environments’, underpinned by ‘taken-for-granted socially constructed knowledge’ about ageing and disease (Lyman, 1989: 604). People with dementia are therefore viewed as ‘social actors’ interacting with others in a variety of settings, including families, day care facilities and long-term care settings, and through these interactions, co-producing ‘shared knowledge’ of dementia distinct from the ‘fixed biomedical reality’ (Lyman, 1989: 604).

The sociogenic perspective of dementia, outlined by Lyman (1989) is further developed in Kitwood’s approach to dementia and care based on the concept of ‘personhood’, looking ‘more to human rather than to medical solutions’ (Kitwood, 1997: 2). Kitwood’s (1989) critique addresses the ‘standard paradigm’ adopted within the biomedical research into dementia which assumes a simple linear causal relationship between neuropathology and dementia (Kitwood, 1989). He argues that the paradigm is inadequate in its explanation of the disease for three reasons: firstly, the neuropathological explanation of the causes of dementia is ‘unsound’ as there can be a substantial degree of change in the brain without dementia, and ‘there can be dementia without significant neuropathology’ (Kitwood, 1997: 35).

Secondly, while acknowledging the role of genes in the causation of the disease, the author nevertheless warns against ‘genetic hype’ emphasising that genes themselves ‘do not cause anything’ but function as a ‘background’ for other causes (Kitwood, 1997: 35). Thirdly, Kitwood (1997) points to the difference between the pace of the progression of neuropathic processes and that of dementia, with the former being relatively slow and the latter sometimes advancing rapidly. Kitwood concludes that ‘neuropathic ideology’ embraced by the biomedical model fails to account for ‘multiple and interactional’ causation of dementia (1997: 36). The major focus of the author’s critique, however, is not on what he calls the standard paradigm’s ‘internal inconsistencies’ but on its treatment of dementia and care in a ‘technical way’, its reliance on ‘medical breakthroughs to come’ without which nothing can be improved, and the resulting ‘deterministic view’ of dementia expressed in such catastrophic images as ‘the death that leaves the body behind’ and ‘no cure, no help, no hope’ (Kitwood, 1997: 37). Thus, argues Kitwood (1997), the standard paradigm offers neither scope to include experiences of real persons living with dementia, their diverse backgrounds and personalities, nor any ideas about effective care and support.

Echoing Lyman’s (1989) call to adopt the sociogenic perspective to dementia, Kitwood suggests a model based on the idea if ‘personhood’ which he defines as ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being’ (1997: 8). This perspective incorporates social and societal factors, such as ‘culture, locality, social class, education, financial resources, the availability or absence of support and services’ as well as social-psychological and interpersonal aspects, such as opportunities for the person with dementia to retain and maintain social relationships, ‘to use his or her abilities, to experience variety and enjoyment’ (Kitwood, 1997: 37). Personhood, maintains Kitwood, can be enhanced by the person-centred approach to dementia care, based on the ideas found in the ‘symbolic interactionism’ theory which views human interaction as a meaning-sharing process enabled by ‘reflection, anticipation, expectation and creativity’ (1997: 87). If adapted, to take cognitive impairment into account, this approach to care can counter the view of people with dementia as behaving meaninglessly and the resulting loss of personhood (Kitwood, 1997).

Kitwood’s perspective has been influential in the development of new models of care emphasising the person over the disease, shifting the discourse from ‘the dementia sufferer’ to ‘the person with dementia’ and improving the understanding of subjective experience of living with dementia (Bruens, 2013). While recognising Kitwood’s significant contribution towards cultural change and social inclusion of people with dementia, Bruens points to a number of limitations in his approach, including ‘the lack of empirical support’ and the need for further theoretical development of the concept of personhood (2013: 86). In the absence of tested methodologies and empirical data, some of Kitwood's ideas could not be implemented in practice, and although dementia care has improved, the validity of Kitwood's methods is still to be verified through further research and application in practice (Bruens, 2013). Another shortcoming of the personhood model, according to Bruens, is that it is tied to the individual's 'micro-environment', omitting broader socio-political factors such as ageism and social inequalities, thus focusing on a 'small-scale reform' (2013: 86). The lack of attention to these broader structural factors, Bruens (2013) suggests, diminishes the model's impact on the transformation of the organisational culture of dementia care, which is influenced by economic decisions around funding, the persistent stigma around dementia and opinions about institutionalised care and autonomy (Bruens, 2013).

Addressing the matters of autonomy and dependence, Bruens (2013) argues that Kitwood's definition of personhood as something 'conferred' upon an individual by others is also contentious, as it positions the person with dementia as a passive recipient of the personhood status which is still contingent on cognition (Baldwin, 2008; Behuniak, 2010). While the humanistic approach and personhood model have effectively challenged the biomedical view of dementia, the exclusion of people with dementia from active participation in everyday life, decision making processes and other forms of discrimination at a variety of levels still persist (Bartlett and O'Connor, 2007; Bruens, 2013). It is argued that Kitwood's model did not go far enough in addressing the enduring structures of social exclusion which can be achieved by drawing attention and giving space to the voice, personal stories and subjective experiences of people with dementia in public debate (Baldwin,2008;Bruens,2013).

Although alternative models of dementia are still under-theorised, and only a few small scale studies which include perspectives of people with dementia exist, frameworks based on the social model of disability, socio-cultural context, the ideas of empowerment, citizenship and a stronger emphasis on the social aspect of dementia are being developed (Downs, 2000; Gilliard et al, 2005; Bartlett and O'Connor, 2007; Behuniak, 2010). Using the social model of disability as a lens in their exploration of approaches to dementia and dementia care Gilliard et al (2005) argue that neither medical nor social constructionist perspectives of dementia can speak up confidently against the marginalization of people with dementia. The authors point to similarities between the medical view of disability and the medical model of dementia, in particular to the perceived ‘state of hopelessness’, victimhood and being seen as ‘beyond help’ (Gilliard et al, 2005: 572, 574). Public stigma around disability shaped by culture and the media and expressed in a stereotyping language is another shared issue, with media reports about dementia largely focusing on the biomedical search for the cure on the one hand, while labelling the condition ‘an imminent catastrophe’ and a ‘form of social death’ on the other (Gilliard et al, 2005; Peel, 2014: 890, 887).

Although the social model of disability has not yet fully extended to cognitive impairment in general and dementia in particular, with some writers arguing that it would be ‘inappropriate to apply the model to older people with mental impairments’ (Oldman, 2002: 799), Gilliard et al (2005) maintain that people with dementia fit into the definition of disability developed by Barnes (2010) who describes it as ‘nothing more complicated than a focus on the economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment’ (2010: 9). Among the barriers experienced by people with disabilities and those living with dementia is the focus on losses rather than remaining abilities within the broader context of a dependency culture, underpinned by the social care resource allocation models based on the cost effectiveness analyses with ‘dependency characteristics’ of the person accepted as the ‘starting point’ (Gilliard et al, 2005; Oldman, 2002: 795).

Outlining positive aspects of seeing dementia through the social model of disability Gilliard et al (2005) highlight an increased awareness of discrimination against people with dementia, a focus on abilities rather than losses, and a better understanding of personal experience of living with dementia. The authors also emphasise the importance of recognising a disabling or enabling role of the social and built environment, however, this point is considered within the wider debate around the issue of impairment. While some social model campaigners have argued that ‘concern with impairment or the body would only distract attention away from how society oppresses disabled people’ (Gilliard et al, 2005: 573), others have critiqued the separation between the body, impairment and disability pointing out that the disembodied view of disability leaves the body and impairment to the authority of medical discourse and calling for the expansion of the model (Hughes and Paterson, 1997). According to Gilliard et al (2005), a recent engagement with both issues of impairment and disability within the social model theory is a positive step for people with dementia, as their impairment does have a considerable effect on their lives.

Combining elements from the social model of disability with those from other perspectives of dementia, such as, for example, the concepts of personhood and citizenship, would enable researchers to construct a holistic approach through which the issues of exclusion, stigmatisation, agency and voice can be addressed (Gilliard et al, 2005; Bartlett and O'Connor, 2007). A broadened framework, closely associated with the social model, will support the move towards the non-tragic view of the condition and provide a new lens through which the subjective experience of dementia situated within a socio-cultural context can be explored (Downs, 2000; DiZazzo-Miller and Pociak, 2015).

According to Downs (2000), one of the under-researched areas within dementia studies generating a growing interest is the socio-cultural context of dementia, traditionally neglected by the biomedical and psychological models with their focus on the individual. Downs (2000) points out that as those living with dementia are a heterogeneous group comprised of people from different social, economic, ethnic and cultural backgrounds, their experiences of and response to the condition will be varied. As the debate about causes of dementia continues and scientists try to establish whether the condition is 'a normal part of neural ageing or a disease of aged neurons', an exploration of the meaning of dementia in different societies and cultures is yet to be undertaken (Downs, 2000: 371). Gaps in research around the influence of socio-cultural factors on the lived experience of dementia, family carers' response and the uptake of supports can be met through the intra-cultural ethnographic studies carried out along the lines of gender, class and ethnicity, as well as comparative inter-cultural ethnographic research (Downs, 2000).

2.2.7. The personal and the political in dementia research and practice

As the biomedical model of dementia is continuing to be challenged by researchers and practitioners whose new concepts are contributing to the rise in awareness about the status of people living with dementia, their experiences of discrimination and stigma as well as to the development of more compassionate care practices, the calls to integrate and combine elements of different concepts of research and practice are growing (Bartlett and O'Connor, 2007; Behuniak, 2010; Baldwin, 2008). Pointing out that discrimination against people with dementia constitutes a public health issue because of its negative impact on the already existing neurological problems as well as personal growth and confidence levels, Bartlett and O'Connor (2007) maintain that only by making personal experiences of discrimination political can the current status of the disempowered group be improved.

Although the personhood approach to dementia has attended to some aspects of the discrimination by highlighting the disadvantages of focusing solely on neuropathology and 'highly developed cognitive functions to the exclusion of other human faculties' (Kitwood and Bredin, 1992: 278), and by considering the influence of interpersonal relations and the personal histories on the behaviour and dementia experience, it has lacked political dimension necessary for situating the individual experience within wider societal structures (Bartlett and O'Connor, 2007). This gap, according to Bartlett and O'Connor (2007), can be addressed by employing a citizenship perspective which views people with dementia as active social agents with power, entitled to the same rights as everyone else. The model is still under-theorised (Baldwin, 2008) and research into how micro level realities such as quality of care and individual coping strategies are interconnected with macro level issues, which include such 'structuring forces' as disability, age, gender, ethnicity and social class is yet to be further developed (Bartlett and O'Connor, 2007: 114).

The citizenship lens, with its focus on enabling people with dementia to maintain their civil, political and social rights, can extend the research agenda beyond dementia care matters, leading to the improvement of their situation in general (Bartlett and O'Connor, 2007;

Cantley and Bowes, 2004). Citizenship is defined as not simply being endowed with rights and having the status of a citizen bestowed upon oneself but, reflecting the shift away from the national model towards more complex forms, is conceptualised as practice encompassing rights, obligations, meaningful political participation and inclusion in one's community (Barnes, Auburn and Lea, 2004; Bartlett and O'Connor, 2007). For people with dementia realising their citizenship may mean being a part of advocacy and self-help groups, participating more prominently in research and putting forward their own perspective to shape the research agenda, and being involved in decision-making processes (Baldwin, 2008).

While some scholars are calling for a more profound shift from the personhood model of dementia to political models based on power (Behuniak, 2010), others argue that combining personhood and citizenship models and developing them further would link the personal and the political, providing a broader lens for understanding and responding to challenges of dementia (Bartlett and O'Connor, 2007; Baldwin, 2008). Applied on its own the citizenship model has a number of limitations, such as lacking 'an individual dimension' and treating people with dementia as 'a homogenous group' (Bartlett and O'Connor, 2007: 113). A more inclusive approach with the emphasis on the human experience of the condition, situated within the network of social relationships (Nolan et al, 2003) and in the context shaped by wider social structures would strengthen 'the anti-discriminatory practice and socio-political research agenda' (Bartlett and O'Connor, 2007: 115).

Chapter Three: Technologies of care

3.1. Introduction

Throughout this chapter I present the literature on the intersections between ageing, technology and biomedicine, explicating social constructions of the older technology user. I argue that at present technology design and development are shaped by ageist views of older people. I conclude the section by tracing critical approaches to the inter-relationships between technology and user.

3.2. 'Technocitizens', ageism, (non)adoption

The dominance of the biomedical view, according to Estes and Binney (1989), has resulted in the acceptance of the model by the wider public and the elderly and their families. The biomedical science is seen as the holder of the solution to the problems of ageing, potentially achieved through 'the purchase and consumption of more and more high cost medical services and technology' (Estes and Binney, 1989: 594). In the light of these developments Joyce and Loe (2010) point to a significant recent growth in anti-ageing medicine and assisted living technologies designed to enable the elderly to age at home. In the market-driven environment, 'ageing in place' aided by technological innovation has become the universal feature in policies on ageing (Mort et al, 2013).

Joyce and Mamo (2006) provide an in-depth analysis of the intersection between ageing, technology and biomedicine adopting the Science and Technology Studies (STS) framework, focusing on its three conceptual tools – 'configuration of the user, material practices and negotiations, and technological design' (2006: 109). The authors highlight the intertwining of the concurrent developments within health and care policies, such as the extension of the retirement age, the dwindling resources for social care and the shift of care responsibility from publicly funded bodies to community and unpaid home care with the unceasingly ubiquitous portrayal of the ageing body as active, youthful, productive and continuously consuming. In this context, the authors argue, it is essential to analyse and critique the role of what Latour defined as 'technoscience' in the construction of the idea of what constitutes 'normal' ageing (Joyce and Mamo, 2006: 100). To illustrate the complex ways in which technologies, science and ageing intersect the authors introduce the image of a 'cyborg', which, they point out, is even more fitting for the description of older technology users than of their usually young, male counterparts, because 'in reality, it is more often aging people who negotiate a complex landscape of technological devices to (continue) active living' (Joyce and Mamo, 2006: 100).

The cyborg metaphor employed by Joyce and Mamo (2006) is drawn from Haraway's feminist (1991) analysis of the interrelations between nature, biopolitics and technologies in the late twentieth century. Haraway (1991) theorises a cyborg as a fusion between an organism and a machine, a biotechnical hybrid existing in the modern medicine and spanning the worlds of science fiction and social reality. Biotechnologies, according to Haraway (1991), have remodelled our bodies and blurred the boundaries between natural and artificial, making it increasingly difficult to delineate what to class as nature. Using Haraway's (1991) analysis as a lens to examine the interrelations between ageing, science and technologies, Joyce and Mamo (2006) argue that science and technologies in many ways determine how ageing is defined, described and experienced. From medicines and pharmaceutical products, such as the hormone replacement therapy, blood pressure pills, and so on to technological devices and gadgets such as walking sticks and fall detectors, to even more sophisticated medical interventions such as plastic knee, shoulder and hip replacements, older people interact with a wide range of technologies on a daily basis (Joyce and Mamo, 2006; Joyce and Loe, 2010). They are the real gray cyborgs or 'technocitizens' who experience, use, shape and adapt technologies within the broader context of the 'technologisation of everyday life' (Joyce and Mamo, 2006; Brittain et al, 2010: 273-274).

Despite this, older people are marginalised from design of new technologies, they are seen as an object of experts' efforts, frail and unable to learn, a risk group in need of monitoring (Ostlund, 2004; Cutler, 2005; Kenner, 2008; Brittain et al, 2010). According to Joyce and Mamo, who analyse the intersection between technoscience and age from the feminist perspective, the view of older people as 'lacking skills and comprehension' to engage with technologies, is more often expressed about older women than men (2006: 115). Thus, older people in general, and older women in particular, are overlooked by technology developers and marketers as potential 'configured users' of supposedly universally usable, neutral technologies (Joyce and Mamo, 2006).

The complex mutual interrelations between ageism and technology are illuminated by Cutler (2005). He notes that ageism affects the ways in which new technologies are developed, marketed and adopted by older people, and in turn, the increasing use of technologies by older people has the potential to challenge ageist attitudes. Cutler's (2005) analysis highlights the circuitous flow of ageist ideas and practice within the processes of technology design, development, marketing and (non)adoption by older people. Starting with the premise that older people are closed to change and unwilling to learn, developers design products aimed at younger, able-bodied market, which makes them unusable to older people. In addition, such factors as self-stereotyping by older people and their low participation as subjects in biomedical research, which Cutler (2005: 69) links to 'negative stereotypes about competence, reliability, and compliance with the requirements' of study, create further obstacles to the acceptance of technologies among older people. Another barrier to older people's adoption of technology, according to Cutler (2005), is the cost: technology is often very expensive and beyond the means of many older people on a limited income. The inability to afford the latest gadgets may be interpreted as a lack of interest in innovation and, thus, will reinforce ageist attitudes. At the same time, such trends as the increase in the ageing population and the 'graying of the labour force' have sparked the industry's interest in the development of products for the growing ageing market with its strengthening 'purchasing power' (Cutler, 2005: 71). In this context technology may be seen as an indicator of the broader economic inequalities between older people, with those who can and cannot afford it occupying the opposite sides of the technological divide.

Negative ageist views of older people, as unable or unwilling to adopt technologies, have been challenged by smaller empirical studies on the acceptability of technologies to older people (McCreadie and Tinker, 2005; Percival and Hanson, 2006; Mitzner et al, 2010, Loe, 2010). For example, McCreadie and Tinker's (2005: 104) study of the use of assistive technologies by older residents of ten social housing providers in England revealed that none of their sixty-seven respondents were ‘technophobic’. Rather, the respondents’ attitudes to the adoption of assistive devices and systems were pragmatic and positive, as long as the technologies were perceived as ‘reliable’ and ‘met a need’ (McCreadie and Tinker, 2005: 104).

The researchers define assistive technologies as ‘any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed’ (Cowan and Turner-Smith, 1999 cited in McCready and Tinker, 2005: 91). Through in-depth interviews focusing on experiences of use and acceptability the researchers collected views of people aged 70 and above on a variety of assistive technologies, including such items as video door-entry systems, fall detectors and environmental alarms as well as housing adaptations. The results formed the basis of a model for understanding how older people experience and use technologies, comprising three key elements – ‘the felt need for assistance’, ‘the perceived usefulness of the AT’, and the interrelations between the use of technology and the sense of personal identity (McCreadie and Tinker, 2005: 93).

The ‘felt need’, according to the authors, must be distinguished from a ‘professionally assessed’ or ‘objective’ need for support, which may only partially reflect the individual’s own perception of his or her physical capability to cope (McCreadie and Tinker, 2005: 105). While some older respondents enthusiastically used assistive technologies perceived as helpful, thus making it evident that the felt need was more important than chronological age, others did not like using AT because they felt no need to do so. The tension between how the need for support is defined by professionals and how it is perceived by the individual may result in situations where assistive technologies recommended or prescribed by professionals are rejected by the intended older user.

Percival and Hanson (2006: 895) provide an example of this, where a local authority’s attempt to install bulk purchased voice prompt devices in the houses of their older residents failed because ‘nobody wanted them’, resulting in wasted resources and a stockpile of unused gadgets. Another tension between the expert need assessment and a felt need arises from how the need for assistance is defined and classified by experts and regulators in the context of shrinking social care budgets in the UK. As McCreadie and Tinker (2005) highlight, if the older person’s need level is assessed as low or moderate, it is unlikely that state support with the installation of assistive technologies will be offered. Thus, even though a person may have a ‘felt need’ which can be met by AT, access to technologies may be limited because the need level may be classed by assessors as not high enough and outside of eligibility criteria. McCreadie and Tinker (2005) conclude that any assessment process must include older people’s preferences, opinions and decisions about AT.

This view is echoed by Brittain et al (2013) who emphasise that technology developments aimed at people with dementia must include their perspectives, and not solely those of carers. As Robinson et al (2009) have demonstrated this can be achieved by adopting a ‘participatory design’ approach, which may allow designers to develop a better understanding of how proposed technologies will be used as well as address design limitations. The technology design the project described had two aims – to create a functional prototype to facilitate independence of people living with dementia, and to use the new technology to enable regular communication between people with dementia and carers, titled ‘KITE or Keep in Touch Everyday’ (Robinson et al, 2009: 495). The researchers addressed the issue of non-participation of people with dementia in technology development by adopting a holistic person-centred approach, involving people with dementia and carers in the design process from the outset to the conclusion. This was done through focus groups with discussions aiming to elicit the participants’ perspectives, meanings and values. The study found that ‘people with dementia are enthusiastic about technology design’, and that their participation furnished the researchers with valuable insights into the product’s technical limitations (Robinson et al, 2009: 501). The researchers point out that facilitating techniques such as meeting in a familiar environment can ease the process, and call for a greater involvement of people with dementia in technology development in future.

The second element within McCreadie and Tinker's (2005: 93) model – 'the perceived usefulness' lends itself to a broader analysis of interrelations between the older user and technologies. The researchers' focus on older people's pragmatic assessments of such attributes as reliability and safety can be extended to include the question 'for whom is AT useful', or who is the 'configured user' written into AT design (Joyce and Mamo, 2006: 109)? Adopting a biomedical view of older people's needs and treating potential users as one 'risk group' to be supported and managed through medical interventions and technologies (Kenner, 2008: 259) may result in mass installations of standardised systems which may, as Percival and Hanson point out 'reflect the vested interests that dominate the new technology developments' (2006: 895). The social model of disability, however, allows for the focus to be directed at what Freund (2001: 690) terms 'a disabling organisation of space'. The scholar argues that although some critics of the social model are correct in their warnings about 'over-relativising' definitions of difference, impairment and disability, the design of space still has an impact on how a body engages with environments, and how these designed environments and spaces may be either enabling or limiting and disabling (Freund, 2001: 692).

Drawing on two different usages of disability – as one's bio-medical and social status, and as a restriction on activity produced by a 'particular socio-cultural context' - Freund maintains that 'not being able to' is a sociocultural construction belonging to a continuum where variations in one's disability are determined by particular contexts (2001: 692). The biomedical model of disability, where one is either disabled or not as measured against an established view of a 'normal' body, is being challenged, according to Freund (2001), by demographic changes. The increase in the aged population, or 'the graying of society' has resulted in large numbers of 'deviant' bodies, which are no longer perceived as 'an other' by non-disabled people (2001: 692). By engaging with 'socio-material culture' of which technology is a part, these bodies bring to light the inadequacy of its 'one size fits all' design (Freund, 2001: 692). For example, McCready and Tinker, who adopt the social model of disability in their study of acceptance of technologies by older people, discuss 'architectural disability', a disability that is produced by the interaction between older people's capacities and their housing (2005: 93). Although the majority of older people in the study experienced difficulties with moving around inside their houses because of housing limitations, these limitations were only revealed during interviews about recently installed alarms which, according to the authors, while improving the safety of the residents ‘did nothing to meet their mobility needs’ (McCreadie and Tinker, 2005: 103).

Brittain et al (2009: 274) argue that all human activity is to some degree technologically mediated, and as a mediator technology has an impact on how the person and the world interact, either by making the world more accessible if it works, or by becoming ‘an interference if it is broken. McCreadie and Tinker’s study has found that older people highly valued technologies that worked ‘properly, reliably and safely’ (2005: 103), while Mort et al (2013) recorded unwillingness to engage with telecare systems among their research participants, because of the systems’ rigidity and ‘punitive’ removals in cases of misuse (2013: 811). A number of technology researchers conclude that technology use is always situated, emphasising the importance of the specific context and ways in which technologies are used (Joyce and Mamo, 2006; Brittain et al, 2009; Mort el al, 2013; Parker and Hawley, 2013). Mort el al (2013), warn against looking to assistive technologies for universal solutions to care provision, no matter how attractive this may seem to industry and policy makers. In a critical assessment of telehealth and telecare trials in England, Parker and Hawley conclude that the answer to the pertinent question of whether telecare reduces hospital admissions is ‘probably not much’ and ‘possibly a little’ (2013: 424). They highlight the lack of high-quality research into technologically supported care and call on researchers to open ‘the telecare black box’ and to ask questions about ‘what works for whom, in what way and in what circumstances’ (2013: 424).

3.3. Technogeographies of care

In their review of 25 years of sociological writings on medical technologies, Timmermans and Berg (2003) draw on the scholarship from the interdisciplinary field of the science and technology studies (STS) to explore the relationship between technology, its users and health care. STS theorise technology as being ethnographically located in the process of its design or use, and therefore studying technology ‘in action’ or from the ‘technology-in-practice' perspective allows to trace its embeddedness in relations existing between other 'practices, groups, professionals and patients' (Timmermans and Berg, 2003: 104). The mapping of the heterogeneous networks which encompass designers, manufacturers, users, components of technologies, materials, support systems, built environment and so on, can reveal how health and care interventions, treatments and or any actions at all are produced (Timmermans and Berg, 2003; Poland et al, 2005). As Poland et al (2005) argue, the technology-in-practice approach is particularly pertinent presently - at the time when health and social care delivery is moved into the 'non-traditional settings' of home and community, and existing 'socio-technical' networks designed around institutions are reshaped and shifted (2005: 176).

The adoption of the technology-in-practice approach as a theoretical tool in the study of care and technologies is supported by other scholars; for example, Milligan et al (2011) argue for its application to the analysis of telecare technologies. The scholars point to the 'social' nature of technologies as they are 'conceived, produced and marketed within complex social arrangements and are materialisations of these arrangements and practices' (Milligan et al, 2011: 348). Therefore, uncovering how care technologies are designed, produced, implemented and experienced by users would provide a deep insight into newly emerging patterns and networks of technologically-supported care (Milligan et al 2011).

Applying the technology-in-practice concept to the analysis of socio-technical networks, Timmermans and Berg (2003) argue that technology should be theorised as one of the actors within 'changing configurations of social and technical elements' (2003: 104). The scholars maintain that treating technology as either a 'blank slate to be interpreted' or a 'super actor stifling all other interactions' is unhelpful; instead, it should be recognised that while technology affects clinical and organisational aspects of care delivery and shapes the actions of others, it is also shaped by the agency of others (Timmermans and Berg, 2003: 104). Thus, by observing technology in practice, it is possible to trace social, technological and other types of transformations that occur within the emerging networks.

Echoing Arkich's perspective on the 'geography or responsibilities' (1992: 207), Poland et al (2005) highlight the pivotal role the sociotechnical networks play in the redistribution of 'knowledge, skills and duties between humans, and between humans and technologies (Poland et al, 2005: 176) thus creating new alliances between people and things. Analysing the depth and extent of this interrelationship, Webster (2002) rejects the idea that today's medical innovations are simply a more advanced set of tools available in the 'medical bag' (Webster, 2002: 446). Drawing on STS scholarship, the author highlights the transformative impact of technologies on people's understanding of health and illness, medicine and the body, which has led to the profound changes in the 'scale, scope and boundaries of the medical portfolio itself' (Webster, 2002: 446). Webster (2002) illustrates the 'qualitative shift' in the relation between the technical and the social using an example of telemedicine and telecare which alter the boundaries of the body itself through the remote diagnosis (2002: 446). Outside of the lab or the clinic, however, the impact of the technical is determined by the context: the social shapes the way technologies are reconfigured and embedded within social relations and networks (Akrich, 1992; Webster, 2002). Drawing on the view of technology as an active transformer of care, Oudshoorn (2011) points to the multiplicity of ways the introduction of technology affects the order of care. The scholar argues against theorising technology as a unified isolated instrument which can be smoothly introduced into a care network, rather technology actively 'creates different forms of care', redefines 'professional and patient identities' and introduces new professional roles reshaping the whole organisation of care (Oudshoorn, 2011: 191).

Examining the interrelationship between the technical and the social, Poland et al (2005) consider how place and relations of power within it mediate and are in turn mediated and shaped by technologies. The authors make an interesting observation of the role of the so termed 'mundane' technologies, such as band-aids, tests, corridors and elevators in the 'structuring and localising' of health and care (Poland et al, 2005: 175). Foregrounding the importance of people's daily practices examined through the technology-in-practice perspective, Poland et al (2005) maintain that understanding how people interact with technologies, comply with established rules or circumvent them contributes to, for instance, successful detection and control of contagious diseases. To demonstrate how power is embedded in the ways the technological interacts with the social, the scholars distinguish between ‘the technologies of surveillance’ and ‘the technologies of enablement’ such as mobility aides and home care devices connected remotely to a hub, which fall into the category of the mundane technologies (Poland et al, 2005: 176). To people living with long-term care needs and receiving care in the non-traditional settings of home and community these technologies might provide both opportunities for an enhanced quality of life, including better mobility, as well as unwanted surveillance and disruption of privacy. Thus, conclude (Poland et al, 2005: 176), technologies simultaneously offer place-mediated ‘opportunities for empowerment, resistance, and the extension of power and social control’.

A power mismatch in how technology is presented to professionals and users is discussed by Roberts and Mort (2008). On the one hand, the promise of independence, autonomy and being able to stay in one’s own home, directed at older people by technology designers and marketers seems empowering; however, on the other hand, many telecare devices and systems ‘seem to be designed to meet the needs of professionals or care managers’ whose main objective is to manage care demands or monitor movements (Roberts and Mort, 2009: 141). This results in a paradoxical situation where older people are cast as passive, surveilled care recipients and simultaneously seen as successfully maintaining independence and ageing in own home (Roberts and Mort, 2009). Similarly, Milligan (2009) highlights tensions that exist between the needs of carers and those of the cared for, engendered by monitoring and surveillance technologies. While enabling technologies may be generally accepted by older people, it is mainly formal and informal carers who may derive benefits in the use of monitoring and surveillance technologies (Milligan, 2009). Researchers therefore should seek to understand who is mostly affected by such innovations and in what way.

In their discussion of relations of power and technology, Poland et al emphasise that technology is not outside of the influences of ‘racism, sexism, classism and other forms of discrimination in evidence in society’ (Poland et al, 2005: 177). Other scholars examining the reordering of care highlight how inequality is reproduced within socio-technical networks (Oudshoorn, 2011; Roberts and Mort, 2009; Milligan, 2009). For instance, Roberts and Mort (2009) point out that the landscape of care into which technologies are being introduced is already a place ‘fraught with trouble and complexity’, where all types of care are ‘deeply gendered, classed and racialised’ (2009: 154). Increasingly in Europe, according to the authors, paid care is delivered by women from lower socioeconomic groups and migrant women (Roberts and Mort, 2009). Oudshoorn (2011) argues that the existing gendered segregation of labour within health and care sector, where nursing and medical assistant professions are largely staffed by women, while men mostly occupy the higher management and clinical professional sectors, is not challenged but reinforced by the new category of telecare. Within the new order of care transformed by technologies women are employed as ‘telenurses’ while men work as ‘telephysicians and supervisors’ thus reflecting the pre-existing gendered hierarchy (Oudshoorn, 2011: 193).

Another aspect of power relations present within health and social care landscape relates to the ‘clinical gaze’ (Oudshoorn, 2011: 10). Highlighting the distributed, dispersed, network shaped nature of technologically delivered care the scholar points out that within such a landscape the traditional role of the primary carer becomes problematic (Oudshoorn, 2011). Care becomes a concern of a number of actors within a range of locations, including the new category of telecare professionals as well as patients themselves, so establishing ‘who controls the clinical gaze’ may no longer be possible (Oudshoorn, 2011: 10). Moreover, the heterogeneity of the users within the network means that a range of conflicting views of technologies, variations in tasks assigned to them and the differences between users’ positions within the landscape may result in an unequal distribution of power (Oudshoorn, 2011).

The unequal distribution of responsibilities between actors within the care landscape is the central point in Oudshoorn’s (2011) approach to the study of telecare. While the network perspective of technologies used by STS scholars (Akrich, 1992) does not take into account the hierarchical nature of interactions ‘among humans and between technological objects and people’ the author’s own approach counters this by introducing geography into the conceptualisation of these interactions (Oudshoorn, 2011: 191). The 'technogeographical approach', argues Oudshoorn (2011) encompasses 'the distribution of responsibilities' among the actors within the network, the attention to lack of agency and power afforded to some actors whose agency is thus diminished, and the importance of place and place-embeddedness of the interrelationships between humans and technologies (Oudshoorn, 2011: 197).

A focus on place is crucial for exploring the role of technologies in the changing landscapes of care. Place may shape how technologies are used or why they are abandoned, and in turn, technologies may produce new care practices, spaces where people and technologies interact and new professional identities thus altering places of care (Oudshoorn, 2011). For example, Milligan (2009) argues that as a result of the introduction of new care technologies into care landscapes care arrangements have shifted from the 'institutional and community-based arrangements to extitutional ones, in which new care providers in places remote from traditional care settings are drawn into the care network' (Milligan, 2009: 90).

The location of the new care relationships within home as well as across virtual and physical space alters the boundaries of the home itself, making them increasingly porous via monitoring and surveillance technologies (Milligan, Roberts and Mort, 2011). Telecare and other remote care technologies, according to Milligan, Roberts and Mort (2011) are 'inherently geographical' as their use changes the order, organisation and the way care is delivered at a distance and through time thus 'collapsing timespace contunuum' (2011: 348).

3.4. Technology and identity

A critical approach to the study of interrelationships between technology and user is an integral part of the wider social analysis of technology (Bijker and Law, 1992). Technologies, argue Bijker and Law, cannot be 'purely technological' as they 'mirror our societies’ and are shaped by a variety of factors – from available materials and design tools to ‘the notions of what is beautiful and worthwhile’ as well as politics and economics (1992: 3). To illustrate this point, the authors draw on the notion of a catastrophe, the moments when technology fails. Technologies are taken for granted when they work well, and users are often unaware of and not curious about decisions behind the design and the multitude of factors that influence the way technologies are shaped. However, the authors maintain, when a disaster strikes the flaws in the design are exposed and people begin to question whether technology could have been better, might not have failed or might have worked differently (Bijker and Law, 1992). After the collapse of the Cypress Structure, a part of the Nimitz Highway in California following the 1989 earthquake, it became clear that the tragedy could have been avoided had the structure been better reinforced. This had not been done because of the lack of funding, which in turn ‘was a result of a complex set of political decisions about electoral priorities and taxation’ (Bijker and Law, 1992: 2). The multifaceted interrelations between what the authors term ‘the technological’ and ‘the social’ can only be understood if heterogeneous factors, such as assumptions of designers, engineers and politicians about the roles of technologies, and the ways in which users adopt, misuse and reshape them are considered (Bijker and Law, 1992: 4).

Akrich moves the analysis of the interrelations between the ‘social’ and ‘technical’ further by theorising this interaction as a constitutive part of ‘heterogeneous networks’ that bring together both human and non-human ‘actants’ (1992: 206). From this standpoint Akrich (1992) challenges the binary division between the descriptions of technical objects by competing epistemological traditions – technological determinism and social constructivism, arguing that neither has enough scope to illuminate the interrelationships sufficiently. While technological determinism ignores the dynamic interactions between ‘what is brought together’ within the network, social constructivism does not recognise objects as actors, positioned alongside humans (Akrich, 1992: 206). When technologists design a product they have to envisage or even try to predict how it will be used and by whom, or as Akrich puts it ‘to inscribe’ their vision of the potential user’s motivations, aspirations, needs, tastes and so on (1992: 208). However, if this script does not reflect the user’s reality and the object is not used, it becomes a ‘chimera’, or something unreal, outside of the network of the human – technology interaction (Akrich, 1992: 208). Similarly, when designers picture potential users having certain roles, or even inscribe those imagined roles within the design itself with the aim to ‘persuade the actors to play the roles proposed for them’, they may find that these roles are resisted, negotiated and reshaped by users (Akrich, 1992: 214).

The idea of objects as actors is illustrated by Akrich through the concept of ‘geography of responsibilities’ produced by technologies through a complex delegation of specific functions to a network of other actors (1992: 207). Drawing on the example of the use of generators in rural Senegal, Akrich (1992) describes a range of actors with specific responsibilities involved in the process, including government officials who purchase the generators, youth groups who distribute them to rural locations and rent them out, those who transport the generators to villagers, who in turn take the responsibility for filling them with oil and fuel. Similar to technology scripts and roles, geography of responsibilities may be resisted and reshaped by those located within its configuration.

The notion that technologies and user identities inscribed into their design are negotiated and resisted is echoed and further expanded by Joyce and Mamo (2006) who combine the notion that technologies hold multiple meanings for different users, known as the concept of ‘interpretive flexibility’ in STS, with the feminist perspective on technology use by older people. The authors call for new research informed by both approaches which should critically examine ‘how heterogeneous older people accept, negotiate, and resist the wide range of technologies in their lives and how their social positions within hierarchies of power variously shape these actions’ (Joyce and Mamo, 2006: 112).

Loe’s (2010) research into the use of technologies by nonagenarian women ageing ‘in place’ or at home addresses the gap in the scholarship on ageing from combined feminist and STS standpoints. As the population is becoming aged and more feminised and the scholarship on ageing, care and technology is growing, a significant body of gerontology literature, Loe argues, tends to use an evaluative approach, focusing on what can be done for older people, how they should be cared for and what kind of ‘universal design products’ should be used in care (2010: 319). However, according to the author, in order to understand how older people create meanings around every day technology use, how they negotiate and shape technologies, an ethnographic approach should be adopted. In the study Loe (2010) combines a symbolic interactionist framework with a lifecourse approach which allows her to explore how nonagenarian women's biographies, social contexts and place interrelate with meaning making around technology use. The STS definition of technologies which includes 'any application of knowledge, including scientific knowledge, such as drugs, classification schemes, and machines (Joyce and Mamo, 2006: 102) is applied in Loe's research to include 'everyday mundane technologies' which are, nevertheless, very important to the women, as they 'enable self-sufficiency, as well as control, independence and health' (2010: 323).

By focusing on three components, central to the women's lives – mobility, communication and nourishment, Loe (2010) illustrates that everyday household technologies are, in fact, assistive technologies. The spectrum of tools, devices and systems used by the women is wide – from walking sticks, walkers, wheelchairs, cars and special shoes and clothing to enable mobility, to phones, telecare systems, computers and special reading devices for communication and intellectual stimulation, and slow cookers and stoves for nourishment. Loe's description of the women's creative use of this broad range of technologies serves as a clear illustration that 'despite what we may expect, nonagenarian women can be and are technogenarians' (2010: 320).

Loe's analysis of self-care routines constructed by the women through the use of technologies is informed by 'doing gender', a concept borrowed from gender studies (2010: 322). She argues that by performing gendered work and enacting what she terms 'lifelong gender roles', such as housework, care work and health work, older women shape, adapt and sometimes reject technologies to achieve self-sufficiency and control (Loe, 2010: 321). Years of gendered work and technology use accompanying it have resulted in women developing 'domain-specific knowledge' around food preparation, connecting with others and maintaining home, which is utilised to successfully perform self-care and to care for spouses in later life (Loe, 2010: 331). Loe (2010) concludes that it is possible for nonagenarian women to age in place and achieve comfort, confidence and autonomy through the use of everyday technologies, however this should be supported by strategies that recognise their agency, the need to maintain social networks, realise everyday routines and remain intellectually engaged.

Neven's (2010) analysis of interactions between robots, older test users and robot developers illustrates how user identity may be shaped by new technologies and how roles scripted by designers are sometimes resisted and rejected. The designers involved in the study derived their initial ideas about their prospective users from literature reviews and came to the conclusion that the users would 'both need and want a health robot' (Neven, 2010: 335). The author points out that the designers did not adhere to the narrow view of older people as a drain on limited resources in the context of an increasing ageing population, rising costs of care and the scarcity of care staff, but made genuine efforts to understand their potential users. As a result, the users were imagined as 'varied', 'having differences in preferences, needs, lifestyles' rather than 'frail, lonely, or forgetful' (Neven, 2010: 338). The robot design also reflected images associated with successful ageing, such as cognitively stimulating games and puzzles for mentally agile users as well as assistive features enabling independent ageing at home. However, these measures did not result in the users' acceptance of the robot, because the designers' 'need and want' representation did not match the images created by the users themselves. Neven reports that 10 out of 12 test participants stated that the robot 'was not for them', but rather for someone they described as 'housebound, old, lonely, feeble and in need of care and attention' (2010: 341). They actively disassociated themselves from this image, and even went further by creating an image of a helpful test user, who is testing the technology for the benefit of other older people who they thought may benefit from it. This alternative identity, Neven (2010: 342) concludes, allowed the test users to perceive themselves as 'successfully ageing', active, healthy individuals, and resulted in their rejection of the identity constructed by the designers and the technology itself.

A study by Aceros et al (2015) into the use of telecare by older people in their own homes has revealed further complex interrelations between the identity of the user and technologies. Drawing on Akrich’s (1992) concept of ‘scripts’ or ‘particular ideas about users and their surroundings’ inscribed into technologies, Aceros et al explore how scripts incorporated within gerontechnologies transform users’ identities and shape ‘specific forms of ageing’ (2015: 104). The professionals in the study accepted telecare devices as ‘helpful’ and believed that by working on older people’s self-concept and presenting the devices as ‘necessities’, they would be able to transform them into ‘good users’ (Aceros et al, 2015: 105). The researchers observed a paradoxical situation, where the professionals in their attempts to convince the users to accept technologies suggested a new identity for them, that of a frail person at risk, in need of daily assistance from ‘helpful devices’ (Aceros et al, 2015: 105). Thus, instead of promoting independence and autonomy, the telecare professionals enforced ageist stereotypes of vulnerability and decline. The researchers found that while some of the users resisted this identity and rejected the technology, others gradually accepted it and began to think of themselves as older people who were losing their ‘faculties, reflexes and memory’ (Aceros et al, 2015: 105). The professionals’ push to align users with telecare systems resulted in the creation of a particular type of user – a compliant older person trained to wear the falls alert pendant at all times. The researchers noted that although the users’ transformed identities were an outcome of many actors working together, including health and telecare professionals, social workers, technicians, the devices, and the users themselves, technology scripts played a significant part in the constitution of a ‘good user’ who has accepted ‘the necessity of constant care at home’ (Aceros et al, 2015: 109).

Chapter Four: Methods of Research

4.1. Introduction

This chapter introduces steps that were taken to examine the range of experiences of living with dementia, caring for a family member with dementia and providing befriending support to people with dementia and carers in Liverpool and North Wales. It also presents the methodological approach implemented to address the research objectives. I begin by outlining the interlinkages between the conceptual framework that guided this research and the methods selected. Next, I explain who my research participants were and how they were approached and recruited. I discuss the ethical concerns and limitations of the study and the process I used to address them. To conclude, I explain how the data were analysed and provide an outline of the presentation of findings in chapters Five, Six and Seven.

4.2. Conceptual and methodological interlinkages

In my study design, I paid particular attention to applying research methods that would enable me to include the voices of people living with dementia. People with dementia have been largely excluded from non-medical research, and their voices marginalised, because of the assumptions surrounding their ability to express themselves and act as research participants (Bond and Corner, 2001). While people with dementia who experience mild symptoms are often aware of their condition, the belief that they are unable to communicate holds persistently, fuelled by stereotypes, negative reporting in the press, and the discourse of tragedy from policy makers (Bond and Corner, 2001). According to Bond and Corner (2001), the dominant scientific biomedical model present in health research allowed for participation of people with dementia and other cognitive impairments as research subjects, undergoing memory tests and cognitive function assessments. However, this type of involvement should not be seen as participation at all, as the research participant is viewed as no more than a provider of ‘test material’ (Bond and Corner, 2001: 96) or ‘a passive vessel of answers’ (Holstein and Gubrium, 1995: 3).

Methods employed in my research project did not include any memory or cognitive tests to determine research participants’ capacity. Rather, the choice of method was informed by a number of theoretical approaches to dementia research.

Firstly, in line with the person-centred approach to dementia care theorised by Kitwood (1997), I took the view that the cognitive impairment that accompanies a diagnosis of dementia must not preclude the person from participating in research. The diagnosis in itself does not mean the person cannot express informed consent or engage in a meaningful competent interaction (Cridland et al, 2016; Meulenbroek et al, 2010); although the issue of consent is more difficult in later stages of dementia.

Secondly, in order to make visible the experiences of people living with dementia in relation to care delivered through voluntary and technological means, I adopted a research approach in line with the social disability approach to dementia, embedding in its design the view that disabling social, environmental and cultural factors impact significantly on how people living with dementia experience technologies and care delivered by volunteers (Gilliard et al, 2005; Wilkinson, 2002). The design of the study and the choice of methods were steered by the idea of conducting research ‘in an inclusive way’ (Wilkinson, 2002: 11) reflecting the principles of the social model of disability.

Thirdly, the theoretical framework I adopted for this research drew on feminist scholarship on care, particularly on studies which stress the interdependent nature of relationships developed in the process of care (Lawson, 2007; Milligan and Wiles, 2010). Furthermore, in adopting a feminist approach to conducting research ‘with or for, rather than about ‘others’ (McDowell, 1992: 407), I aimed to make ‘visible and audible’ the marginalised experiences and knowledges of people with dementia and their carers (Rose, 1997: 308). Whilst not specifically focusing on gender, I followed a feminist approach in my research through aiming to include those whose voices and knowledges are often subjugated within dementia research (Haraway, 1991; Hesse-Biber, 2012). ‘Doing geography’ from the feminist perspective does not necessitate the use of distinctive methodological approaches, (Cope, 2000: 53). Rather, the central principle of a feminist epistemology is to uncover the ways in which knowledge about ‘the other’ is produced, reproduced and legitimised, and it is this critical approach that shapes the research questions and imbues the methods of analysis and interpretation that I adopted (Cope, 2002). ‘The other’ in this study are the people who experience socially and spatially constructed forms of oppression based on their age, disability (dementia) and those involved in caring relationships with these people (Cope, 2002).

4.3. A qualitative case study approach

As the previous chapters have suggested, living with dementia, providing care to a family member with dementia, and growing older in place involve multiple experiences and therefore require an approach to research design informed by looking through ‘variety of lenses’ and perspectives (Baxter and Jack, 2008: 544). In order to fulfil my research objectives, presented in Section 1.2 of this thesis, I endeavoured to reach and speak to a range of participants, including people with dementia, family carers, volunteer befrienders, technology developers and health and social care professionals. According to Yin (2015), if a research project sets out to answer ‘how’ and ‘why’ questions, the appropriate method is a qualitative case study (Yin, 2015: 10). For this project, a qualitative case study approach is suitable because it sets out to illuminate how people with dementia and carers may perceive voluntary and technologically supported care, and why their understandings are vital for shaping decisions about dementia care at a range of scales.

The use of qualitative methods, such as in-depth interviewing and participant observation in studies concerned with the complex and diverse experiences of older people with cognitive impairments has been seen as vital by social and geographical researchers (Bond and Corner, 2001; Carmody et al, 2015; Milligan, 2000; Andrews et al, 2006). Highlighting the double disadvantage of ageism and stigma around dementia experienced by older people with memory impairments, Wilkinson (2002) points out that people with dementia remain ‘a silent and excluded voice’ in research (Wilkinson, 2002: 9). Inclusive qualitative methods already in use in feminist and disability studies, according to Wilkinson (2002), should be applied in dementia research in order to make the person heard. Employing qualitative methods of in-depth interviewing and participant observation, this study aimed to 'allow care and time' to facilitate a meaningful participation of people with dementia (Wilkinson, 2002: 17).

Baxter and Jack (2008) point to the usefulness of the case study approach to health research because of its flexibility and rigour which are instrumental in the evaluation and development of theory, as well as practical programmes and interventions. Moreover, the strength of the approach lies in the 'close collaboration between the researcher and the participant' - which enables the participants to tell their stories and, in so doing, provides a means for the researcher to understand the phenomena under study and the participants' actions through these accounts (Baxter and Jack, 2008: 545). Outlining the scope of a case study approach, Yin (2015) offers a twofold definition: firstly, the case should be a contemporary 'real-world' phenomenon investigated in depth; secondly, the boundaries between context and the phenomenon being investigated are not easily drawn. Both these conditions apply to this research. First, the prevalence of dementia and challenges in the provision of dementia care are 'real-world' phenomena I have sought to address in depth. Secondly, the contextual conditions in which this study has taken place, such as major transformations in welfare policy and provision, reduction in public spending on social care, the emergence of multiple care providers, including private and voluntary organisations, and technological innovation in health and social care, have a direct impact on the phenomena under study.

The case study for this research centred on a third sector organisation providing befriending and companionship services to people living with dementia and their carers who acted as a partner in this collaborative PhD research project. The multi-local case partner organisation provides a range of services to people of all ages with varied care and support needs. The scope of the study was further narrowed by the selection of particular programmes delivered by the partner organisation. This research therefore explores the experiences of people with dementia and carers who receive dementia support services from the partner organisation. The services are provided by the partner organisation in two different locations – Liverpool and North Wales.

4.4. Data Collection

4.4.1. Preparation

In total, I carried out 41 in-depth interviews with 44 participants. I provide details about these in the tables below. In addition, in preparation for the interviews I carried out 15 participant observations. Only one field diary record of a participant observation was analysed thematically, contributing to the findings of this research outlined in detail in Chapter Seven (section 7.4), where I discuss ‘gatekeepers’ and ‘advocates’ of assistive technologies, and analyse how technology adoption or abandonment by older users is affected by how those around them may perceive older people’s ability to use technology items.

I undertook the other 14 participant observations in preparation for the interviews. I felt this was an important part of the collaborative aspect of my research, as I wanted to give some of my time on a voluntary basis to my future research participants and build a relationship with them before engaging them in the interviewing process. In the course of these preparations, I supported befriender forums and meetings held by the case study partner and lent my hand (and on one occasion my bank card) when shopping for refreshments and cakes prior to the meetings. I visited the Museum of Liverpool with the Luncheon Club members and joined in the ‘Memory Suitcases’ session where we all went through some museum artefacts and reminisced. I helped to serve hot lunch at the Club’s meetings and called taxi companies afterwards to help the older members to get home safely. Although I did not use the data collected during these activities, I gained many allies and became a familiar face to people with dementia, carers and befrienders, who later on were happy to give me some of their time and to speak with me about their lives.

Table 4.1. List of interviewees – professionals

Pseudonymised initials	Professional capacity / role	Interview themes
TS	Senior member of staff at a local Clinical Commissioning Group	Responsibilisation of care
UJ	Head of Services, case partner organisation	‘Doing more’ for one’s family members
MT	Service Manager, case partner organisation	Over-reliance’ of ‘patients’ and ‘service users’ on the NHS and social care services
RL	Digital Inclusion Coordinator, Trade Union	Self-management’, ‘self-care’, responsibility for own health
JR	JR, Service Development Worker, Companions scheme, case partner	Reasons for technology adoption and abandonment by people with dementia and carers
GA	Project Worker, Befriending scheme, case partner organisation	‘Successful’ ageing in place
HR	Project Manager, research hub in the North West of England	‘Over-promises’ of technology
SMA	Senior Manager, Befriending scheme, case partner	Blurring of boundaries between care, friendship and befriending
JST	A warden at a semi-independent housing scheme	Definitions of ‘care’. What should not be classed as ‘care’
DM	Social Worker, case partner organisation	Balance between technologically and human – delivered care
HS	Assistive Technology Worker, case partner organisation	‘Tech can’t solve everything’
AM	Home and Community Service Manager	Self-management of long-term conditions with telecare technologies
DL	Senior Manager, case partner	Overview of case partner’s befriending scheme
OL	Self-identified ‘distant’ carer for parent with advanced dementia and professional at a health, innovation and technology development hub	Technology seen as necessary and desirable in provision of health and care. Technologies facilitating care at distance but older people still prefer face-to-face support.

Table 4.2. List of interviewees – carers[2]

Pseudonymised initials	Key characteristics	Interview themes
OL	Self-identified ‘distant’ carer for parent with advanced dementia and professional at a health, innovation and technology development hub	Balancing caring for own young family with caring for a parent with dementia at distance
CA	Carer for a spouse with advanced dementia living at home. Luncheon Club	Adoption of assistive technologies. Faith as a source of resilience. Changes to identity as a result of becoming a carer.
V	Carer for a spouse with early stage dementia living at a sheltered housing scheme	Administrative aspects of care are very time consuming.
BR	Carer for a spouse with advanced dementia living in a care home	Impact of dementia on carers’ mental and physical health. Carers’ social isolation. Home as a ‘dangerous’ place for people with dementia and carers
PD	Carer for parent with advanced dementia living at home	Family ‘dynamics’ and why distance should not be a hindrance to care provision by family members
WL	Carer for a parent with advanced dementia living in a sheltered and adapted housing scheme	‘Fighting’ for access to statutory care provision. Carers’ role in facilitating a transition to a new place for the person with dementia. Place attachment.
LN	Carer for parent with advanced dementia, living together. Luncheon Club	The importance of staying physically well for carers of people with dementia. Monitoring and maintaining own health.
AF	Carer for parent with advanced dementia, living apart but in the same street	Attachment to place enabled by a ‘supportive community’
SC	Carer for a parent-in-law and Befriender at case partner organisation	Family members expectations around proximate carers’ responsibilities for care provision. Blurred boundaries between friendship and befriending.
WJ	Carer for parent with advanced dementia, living in a sheltered housing scheme	Assistive technologies adding an extra layer of complexity into a care relationship. Impact of technologies on micro geographies of home.

---

[2] Please note that one of the carers included in Table 4.2 is also a professional who was interviewed in both capacities. This carer is included in previous Table 4.1. Another carer volunteered as a Befriender at the case partner scheme and is also included in Table 4.4. below.

Table 4.3. List of interviewees – people with dementia

Pseudonymised initials	Key characteristics	Interview themes
JK	Person with early stage dementia living alone in a spacious house. Accesses services of the Companions scheme in North Wales.	Autonomy, independence and identity. Types of independence, e.g. financial. Simple house modifications and 'the feel of the home'.
MO	Person with early stage dementia, living alone at home. Accesses services of the Companions scheme in North Wales.	'Placed' technology – adoption and abandonment. Desired house modifications and choosing to stay at home.
JB	Person with early stage dementia, living in own home with a spouse. Accesses services of the Companions scheme in North Wales.	Using familiar household technology items. Hobbies, pets and identity. Person with dementia caring for the carer with health problems.
PS	Person with early stage dementia, living in won home and caring for a spouse with severe mobility issues and other health conditions. Accesses services of the Companions scheme in North Wales.	Changes to one's identity through the ageing process. Participation in community life and maintenance of 'social infrastructure' as coping strategies.
M	Person with early stage dementia, living in a sheltered accommodation. Accesses befriending scheme in Liverpool.	Creating new experiences through visiting places with a befriender
KS, WB, VA	Persons with early stage dementia, all living at home alone but within a walking distance of family members who are carers. Access services of the Companions scheme in North Wales	A group interview with three friends. Themes: 'feeling lucky' because family members live close by. Perceived need for technology items balanced against cost. Transition into residential care as the least preferred option. Importance of hobbies and looking after pets for maintaining sense of identity.
SM	Person with early stage dementia, living at home with spouse.	Simple home adaptations seen as enabling and perceived as 'useful'.

Table 4.4. List of interviewees – technology developers and befrienders

Pseudonymised initials	Role	Interview themes
TD, ZM, SG, TR	Technology developers based in Liverpool, focusing on designing and implementing digital technologies for health and social care.	• Technology will replace human workers in health and social care sectors, similarly to all other industries. • Health and social care sectors are difficult to 'break into' for new developers because commissioners prefer well-established providers • 'Co-creation' is a buzzword for some developers whilst others engage in it as an established practice when developing new products • Paternalistic approach to technology design and implementation and its impact on older users
BS, SG, SC, LST, PR, CDS, DPL	Volunteer befrienders in Liverpool	• Blurred boundaries between befriending and friendship. • Assumptions about older technology users with dementia and 'user inscription' and its impact on adoption or non-adoption of technology by befriendees with dementia • Assumptions about older people as 'not interested or not needing' technology • Befrienders as 'gatekeepers' and 'advocates' of technologies • Transgressing boundaries of the role through performance of social care • The impact of shared spaces and memories on friendship bonds

As a qualitative, case study approach, this research does not aim to represent all people living with dementia and carers. Instead, conclusions drawn from this case study are ‘analytic’ in nature (Curtis et al, 2000: 1002), contributing to the theoretical concepts and range of experiences that are visible in relation to volunteerism in dementia care, the intersection of social care and technological innovation, and the complex spatial interrelations produced through these interactions.

To address the research objectives, I drew on the qualitative health research tradition, (Morse, 2012) in which earlier dementia research has explored the impact of the condition on individuals, carers and families, using in-depth interviewing as a key methods (Clarke, 2001; Carmody et al, 2015). My study set out to collect rich data about experiential aspects of dementia, technology use, volunteering and care, and to answer the ‘why’, ‘how’ and ‘what’ questions about living with and caring for someone with dementia (Neergaard et al, 2009: 2). Furthermore, accessing lived experiences and expectations of carers and people with dementia through in-depth interviewing contributed to the collection of evidence for evidence-based service delivery embraced by the Befriending Scheme at the partner organisation (Cridland et al, 2016). While collecting a range of perspectives through interviewing – those of people living with dementia, carers, technology developers, befrienders, staff and other stakeholders, I was not seeking to obtain one ‘true’ account of the phenomena under study. Rather, informed by feminist and poststructural theory on the production of knowledge and meaning as ‘partial’ ‘situated’, produced in and shaped by specific circumstances (Rose, 1997: 305), and co-constructed, in the case of qualitative interviewing, by the researcher and the interviewee through the interaction, performance and negotiation of identities (Tarrant, 2014; Grenier, 2007), I sought to explore the multiple different experiences of dementia and dementia care. Although the accounts and cases collected for this study through in-depth interviewing are therefore non-generalizable, they provide a context-specific insight into the interrelationships between care, voluntarism and technologies.

4.4.2. Recruitment of participants

As this study was carried out with a close collaboration with a case partner, initial recruitment activities were focused on users of one of the partner organisation's schemes. At the time of the recruitment stage the scheme supported around 10 people living with dementia and their family carers. The scheme recruited and trained volunteer befrienders who visited people living with dementia in their own homes with or without family carers present. The befrienders and befriendees also undertook trips out – to museums, cricket matches, day centres and arts and crafts group in line with the wishes of the person with dementia. The scheme was free to use to people with dementia and carers, and the case partner organisation covered the volunteers' travel expenses and lunch.

My recruitment activities focused on people with a diagnosis of dementia referred into the scheme, who were receiving befriending visits or those who have been placed on the waiting list. The two inclusion criteria were: that participants had received a diagnosis of dementia, and that they were in early stages of the condition. For carers, the only inclusion criterion was that they cared for a family member living with dementia; whether the person with dementia still lived in his or her own home, with the carer, or in a care home was not relevant for the study.

As the exploration of responses to technologically delivered care is one of the study's objectives, I considered introducing 'assistive technologies use' as one of the inclusion criteria for the recruitment of participants. However, having applied the inclusion criteria outlined above, I found that my sample of potential research participants had shrunk significantly and that the addition of 'the use of assistive technology' to the criteria would have only reduced the sample further. To maintain the sample size, and to ensure the inclusion of as many people with dementia as possible from the pool of the case partner's service users, I thus included those participants who did not use assistive technologies. Within the interviews with these participants not using assistive technologies, their reasons for non-use were explored.

As mentioned above, one of the exclusion criteria was the stage of dementia – with only individuals with dementia at mild stages included in the study. While I attempted to facilitate communication with research participants with dementia by matching the research tools to their capacity levels, I was concerned that I would not be able to confidently establish whether the participation of a person with severe dementia was truly consensual. As Murphy et al (2014) note, the inclusion of persons with all stages of dementia in research is crucial for understanding their perspective, researchers must be aware of the differences in the ‘experiences and the needs of people with dementia at the mild, moderate and severe stages’ (Murphy et al, 2014: 16). Keeping this in mind, the results of the study speak for people with moderate or severe dementia, as their experiences of voluntary care and assistive technologies may be significantly different (Tanner, 2012). In recognising the challenges of consent in these contexts, scholars such as Clare *et al* (2008) suggest that utilising strategies such as observation and interviews with carers will be beneficial for a better understanding of the context in which subjective experiences of people with dementia are created (Clare et al, 2008). Although no people with moderate or severe dementia participated in the study, family carers of people with advanced stages of dementia were interviewed. They were invited to take part in the study in their own right as carers, and their insights into their family members’ experiences of assistive technologies and befriending were sought during interview.

To extend the participation in research to a wider range of the Scheme’s service users, I used an outreach recruitment approach recommended (Wilding et al, 2013; Cridland et al, 2016). My outreach activities included delivering two talks about dementia – one on the general topic and one specifically focused on my research -, to a local older people’s association, and another talk to staff and service users from a dementia support service run by the case partner organisation in Wales. Alongside this, I attended talks at two carers’ coffee mornings and a forum. These activities were fairly informal, facilitated by a personal contact, face to face communication and the use of the ‘non-technical research language’ (Cridland et al, 2016: 1777). In all my talks, I outlined potential positive outcomes of the study, such as the improvement of the organisation’s dementia services guided by the participants’ voices, and the use of research findings in fundraising applications which would support the continuation of the service. I also shadowed befrienders’ visits to the homes of people with dementia and accompanied befrienders and befriendees on their visits to support groups run by a local football club and the Museum of Liverpool Life. The outreach approach proved to be effective, as the potential participants had an opportunity to get to know me, to ask questions about taking part in the study, to consider whether to give their consent, and often to make an interview appointment on the spot.

I approached the case partner’s dementia service based in North Wales to widen the pool of potential research participants due to the small number of service users supported by the Befriending Scheme in Liverpool. The service in North Wales supports people with dementia by matching them with a companion who is a paid self-employed worker and not a volunteer befriender (as is the case in Liverpool). The companion, and two people with dementia, meet once a week for shopping, accessing community services in the area, and engaging in leisure activities such as cinema trips, visits to garden centres and so on. The referral pathway is similar to that of the Befriending Scheme in Liverpool. In total, nine participants living with dementia were recruited, with two based in Liverpool and seven in North Wales. All of the eight family carer participants in this study were recruited in Liverpool. Although this study did not set out to draw comparisons between the two services in the two locations, I shall nevertheless discuss the impact of the geographical location on the findings in chapter Five.

Following a mapping exercise with a senior manager at the case partner’s Befriending Scheme who helped me to identify potential research participants, staff members employed by the dementia befriending service, befrienders, technology developers and other stakeholders were recruited. All befrienders active at the time of the commencement of research activities and a number of former befrienders were invited to take part in the study. I attended three befriender forums, the first one in a dual capacity of a researcher and volunteer befriender, and the subsequent two as a researcher only. At the forums, I made short presentations about my research to the befrienders and invited them to participate. Following the forums, I contacted each befriender individually to arrange interviews. These were conducted in a variety of locations – including the case partner’s offices, at the university, and in cafes close to where some of the befrienders live. When arranging interviews with volunteers, I was mindful of their time commitments: some of the befrienders have to juggle family, work and education commitments in addition to their voluntary activities. I was therefore very flexible with dates and times of interviews and was prepared to rearrange our meetings if the interviewees had to cancel, sometimes at a short notice.

Members of staff invited to take part in the study came from a range of positions within the organisation – from front-line workers responsible for carrying out interviews with prospective volunteers, befriender assessments and matching, undertaking home visits to befriendees' houses and delivering technology training to community organisations, to the coordinator of the scheme, the Manager of Wellbeing Services, and the Chief Executive Officer of the organisation. Gaining access to the members of staff did not present significant difficulties for two reasons: firstly, I was a familiar face in the case partner organisation and the Befriending Scheme as I previously worked within the scheme and volunteered as a befriender after my employment ceased; secondly, it was agreed that research output would be shared with the organisation for the use in service evaluation and future funding applications.

Organisations working in the field of health and care technology development were identified through the mapping exercise with a senior manager at the case partner and through my attendance of meetings organised by a partner organisation within a Europe-wide project designed to promote cooperation between technology developers and dementia care providers (Innovate Dementia UK http://www.innovatedementia.eu/en). The Befriending Scheme is embedded within a UK government funded programme, led by a local Clinical Commissioning Group, whose purpose is to 'enable people to live independently' through the use of telehealth and telecare technologies (Dawson, Cumming and Hull, 2013:1). Through this partnership, the scheme has engaged with a number of small local technology start-ups and trialled their digital products designed to support dementia care. The companies form a 'digital tech cluster' located in the Baltic Triangle area of Liverpool which serves as a hub for creative digital industries (Technation, 2015: 82). The independent technology developers collaborate with the NHS and large social care providers through an e-health cluster whose coordinator also took part in the study.

4.4.3. Sampling methods and sample size

In this qualitative study, the focus of the analysis was a pre-specified case, therefore case selection was not relevant for the purposes of the research. Instead, 'within case' sampling was applied where the selection and choice of potential participants was carried out within the case partner's services (Curtis et al, 2000: 1002). As the purpose of this study was to carry out an in-depth exploration of complex responses of people with dementia, and carers, to the changing landscapes of care characterised by voluntary care and technological innovation, nonprobabilistic or purposive sampling approach was employed (Teddlie and Yu, 2007). This approach allows for the collection of in-depth information from a smaller number of selected cases, particularly when research involves populations considered to be 'hard-to-reach' or 'stigmatised' (Greg et al, 2006: 61). Within the approach, the criterion sampling method was selected to further define the sample and to 'select cases that meet some predetermined criterion of importance' (Patton, 2002: 238). The predetermined criterion for participants with dementia, carers and befrienders was being in some way connected to the case partner either through the receipt of the Befriending or another dementia support service, or by providing such a service in a voluntary or self-employed capacity.

Following the study design recommendations of Cotrell and Schulz (1993), -who argue that a small sample size is appropriate in research with this population of people with early-stage dementia -I identified a sample of people with dementia and carers supported by the case partner organisation, based on the inclusion and exclusion criteria outlined in section 2.1.1. The selection process was also supported by the manager and the coordinator employed by the Befriending Scheme, who contacted some of the carers over the phone to arrange a preliminary meeting where I could introduce myself, describe my research and invite the person to participate. A total of nine people with dementia and eight carers (four of whom were spouses and four of whom were relatives (adult children), completed 14 research interviews between July and November 2016. There was one spouse/carer dyad. Not all participants with dementia had a differential diagnosis; some had undergone an assessment and were waiting for their results, while others, even though they had received a diagnosis, referred to dementia as ‘memory problems’, or preferred to say they did not have the diagnosis or experience any memory issues. I shall discuss the challenges presented by some emotional responses to the diagnosis on the data collection activities in Section 4.4.5 below, where I further discuss the interviews with people with dementia and carers. People with dementia and carers were offered the opportunity to be interviewed either together, separately or both. One couple chose to be interviewed together, in two other couples spouse carers declined to be interviewed, with one carer leaving the house to meet with friends while I interviewed her husband, and the other carer being present but not speaking while the interview with his wife was being carried out.

A ‘Referral’ or ‘snowball’ sampling technique was used in the selection of respondents from the pool of staff employed by the case organisation, technology developing companies and other stakeholders, such as social care commissioners, digital inclusion professionals and key individuals within the local e-health cluster (Marshall, 1996: 223). Key informants identified through the mapping exercise described above were asked to nominate other candidates who might offer an insightful contribution to the research questions and, as result, increasing the sample size (Trotter, 2012). In total, 28 volunteer befrienders, technology developers, staff, and other stakeholders participated in the interviews. Of the 28 participants, nine were volunteer befrienders, nine were members of staff at the case partner organisation, six were professionals and four were technology developers.

4.4.4. Settings for the interviews

Being able to make decisions about the place and the timing of research activities is linked to the feeling of control over one’s participation in a study (Cottrell and Schultz, 1993). It has been suggested that a degree of control over where research takes place may be relinquished by the researcher in order to make the research process more collaborative and inclusive (Hubbard, Downs, Tester, 2003). A number of scholars recommend using neutral territory that is familiar to people with dementia -such as people’s own homes -and their advice is also to avoid conducting interviews in clinics and GP surgeries, as such places may be associated with clinical assessments and may evoke a feeling of lack of control amongst participants. (Clarke, 2001; Cridland et al, 2016; Cotrell and Schultz, 1993).

In my study, the decisions about where and when interviews took place were made by the participants with dementia and carers. There were three sites where interviews were conducted: individuals’ homes in Liverpool and North Wales, a local town hall where the older people’s association met regularly for lunch and activities, and a meeting room in the offices of the case partner’s dementia support service in North Wales. Each interview site presented its advantages and challenges to the data collection process and impacted on my interaction with research participants. I found myself in agreement with Cridland et al (2016) who point out that when the focus of the interview is on ‘life at home’ conducting the interview at the person’s place of residence may have a number of advantages: firstly, the interviewees may feel more comfortable in a familiar environment and safe to talk openly about their experiences; secondly, they may rely on ‘environmental cues’ which may prompt memories (Cridland et al, 2016: 1778). I conducted 7 interviews with people with dementia and carers in their own homes. I found that when discussing assistive technologies or adaptations made to the house, often my respondents would take me on ‘a tour’ to show me their ‘tech’, such as telecare hubs, alarms fixed to walls, handrails in bathrooms and outside of front and back doors, and so on. When describing difficulties they experienced when providing personal care to their family members, carers would point to the areas of the house which presented these challenges, for example, a staircase that their loved one ‘had forgotten’ how to use, a step by the kitchen door that had caused a fall, and food and cutlery cupboards that had to be locked. Home interviews gave me an opportunity to see the person, as Edwards and Holland (2013) put it, ‘in context’ - to observe their interactions with material objects present within the private space of the home, and to add ‘an ethnographic dimension’ to the data generated through the interviews (Edwards and Holland, 2013: 45).

Interviewing at home also affected the dynamics of power present within every qualitative interview situation (Edwards and Holland, 2013). The assumed 'asymmetries of power'(Edwards and Holland,2013) -where the researcher sets the tone and controls the situation, and the interviewee is positioned as a vulnerable subject, are shifted in qualitative interviews, creating a complex 'interview dance' (2013: 78). The power shifts arise from the loose and minimal structure of an in-depth interview and emotional interdependencies created in the course of an interview, where the researcher engages in emotional labour to build rapport and trust and whereby a shift from 'a knowing expert' to 'a vulnerable knowledge seeker' may take place a number of times over the course of the interview (Edwards and Holland, 2013: 78). I felt that being invited to a person's home at a time chosen by my respondent, who kindly agreed to speak to me and was free to stop the interview at any time and ask me to leave, placed me in the latter category. Although I outlined potential benefits of taking part in the study to my research participants, I was aware that I was reliant on their kindness and good will, as personal benefits of participation were somewhat intangible and may have seemed irrelevant to some of the interviewees.

One of the disadvantages of conducting interviews in participants' homes of which I became aware, was the lack of control on the part of the researcher over who might be present at the interview. This point is not made in relation to the carer-person with dementia dyads -as all research participants were asked whether they preferred to be interviewed together or separately -but refers to the presence of 'others', such as volunteer befrienders, service coordinators and other members of staff employed by the case partner. The presence of these other people brought complications into the interview process on a number of occasions. At two separate interviews when members of staff and a befriender came with me to the interviewees' houses, I had to ask my hosts whether we could conduct the interviews in private. This resulted in the interviewees asking the befriender and the member of staff to leave and to return later. On one occasion, however, a senior member of staff, who drove me to the interviewees' house when I conducted interviews in Wales, decided to stay and engaged in a conversation with the person with dementia and carer about the quality of the service they were receiving. I could not ask the member of staff to leave as it seemed the research participants were enjoying the conversation. They had a good relationship with the member of staff who regularly visited them, while I was relatively unfamiliar. Unfortunately, the interview which took place after the discussion about the service, and still in the presence of the member of staff, was cut short by the interviewee who told me she and her husband 'were fine' and did not feel like answering any questions. I stopped the interview and the conversation returned to the quality of the service and staff visits.

The two other main interview sites also posed relative advantages as well as challenges. For instance, although I had access to a private quiet room at a local town hall which I could use for interviews, I was only partially successful in maintaining confidentiality of the research participants. As I had delivered a talk to the group about my research at my first meeting with them, the attendees were aware that the focus of my research was dementia care. At a meeting that took place the following week a number of people spoke to me about taking part in the study. They explicitly stated that they wanted to talk to me, so dates and times of interviews were arranged. All participants wanted to be interviewed during the association's meetings in the town hall and, as such, this arrangement did not put any additional demands on their time. For the interview, I and one of the participants would leave the meeting and go into the quiet room in the building. This meant that the rest of the group were able to see who is taking part in the study into dementia care. Although I had been assured by the group's coordinator that this did not present a breach of confidentiality, and that the group discussed dementia related issues regularly, I asked each of my participants whether they were concerned that the rest of the group might assume they or their family members had dementia. I reassured them that their account would not be shared with anyone within or outside of the group, and that all accounts were anonymised. All research participants agreed to proceed with the interviews. This situation indicated to me a need to discuss confidentiality with participants at several points in the interview process. I followed Forbat and Henderson's (2003) recommendations - who suggest having such discussions when arranging interviews, at the beginning and at the end of the interview. Confidentiality issues were, accordingly, covered at the beginning of the interviews when the research participants went through the information sheet and consent form, and at the end of the interviews when I asked the participants whether they wanted to see transcripts.

I conducted a group interview with three people with dementia in an office of the case partner's services in Wales. The participants were service users of the dementia support scheme and chose the place and time of the interview themselves. The interview was conducted in a meeting room, and at the beginning the service coordinator and one of the companions were present. In order to maintain the participants' confidentiality and to create an atmosphere of trust and openness, I politely asked the members of staff to leave. During the interview I was reminded that I had not anticipated the challenge of 'physical limitations' (Wilding et al, 2013: 553). Although I used larger font in the information sheets and consent forms, I had not warned my research participants in advance that there would be paperwork they would need to read and sign. One of the participants could not read the documents as she had forgotten her glasses, so she had to borrow her friend's glasses to read through the forms. I also read the text of the forms out loud, and asked her whether she was happy to proceed.

Although all three interviewees had received a diagnosis, one of the participants was unhappy with the word 'dementia' included in the consent form. She stated that she did not have dementia, but only occasional memory problems. I explained that people with memory problems were also welcome to participate, and asked her whether she was still interested in sharing her insight with me. The interview went ahead, however, I had to avoid using the word dementia throughout. I subsequently amended the information sheet and the consent form replacing the word 'dementia' with 'memory problems'.

4.4.5 Interviews with carers and people with dementia

In preparation for the interviewing, I designed a number of participant information sheets outlining the aims of the research and the nature of participation. The information sheet intended for people living with dementia was reviewed by a person with an early stage of dementia, a carer and a befriender. I amended the document in accordance with the feedback provided by the reviewers. Cridland et al (2016) emphasise the importance of using appropriate language when recruiting participants with dementia with advice to pay close attention to terminology used to address potential research participants. When trialling research paperwork for people with dementia I hoped to address sensitive issues around the use of terminology, in particular the use of the word ‘dementia’ and other terms associated with memory loss. A number of studies with people newly diagnosed with dementia have highlighted negative reactions to the diagnosis, including fear, shock, anger, depression, sense of loss, and often an active denial of the diagnosis (Steeman et al, 2006; Robinson, Clare and Evans, 2005; Faranak et al, 2007). Although the diagnosis disclosure may have positive consequences, such as a sense of relief and a better decision making around accessing care and treatment (Faranak et al, 2007), often memory loss may undermine the person’s perceptions of security and autonomy resulting in a fear of loss of personal identity (Steeman et al, 2006). It must be noted that responses to the diagnosis of dementia vary from one person to another and are a result of many factors, including the stage of dementia as well as the social context; denial is considered to be a part of a self-protecting strategy to deal with confusion and changes (Faranak et al, 2007; Steeman et al, 2006). Acceptance is described as a slow continuous and cyclical process of adjustment to loss, characterised by setbacks (Robinson et al, 2010). It is suggested that when communicating with potential research participants with dementia, investigators should try to avoid the use of stigmatizing language, both in written materials and while conducting interviews, and thatusing the term ‘memory problems’ rather than the word ‘dementia’ may reduce the impact of the felt stigma (Garand et al, 2009; Beattie et al, 2004). The reviewer of my paperwork for participants with dementia did not make any suggestions relating to the use of the word ‘dementia’ in the information sheet and the consent form, and I therefore did not remove it from the documents. The use of the word ‘dementia’, however, resulted in strong objections from two research participants whom I interviewed later: one individual initially refused to take part in the interview, having previously consented, as soon as she encountered the word ‘dementia’ in the information sheet. After a discussion and reassurances that my study was open to people who may experience ‘difficulties with remembering things’, the person agreed to speak to me and we proceeded with the interview. I refrained from using the word ‘dementia’ in the interview and amended the paperwork soon afterwards. On another occasion, I was introduced to the potential research participant by a member of staff as ‘the student who is researching dementia’. Before we could move on to the paperwork the participant explicitly stated that he did not have dementia, only some ‘memory problems’, and that he therefore could not take part in the study for people with dementia. Although the individual had received the diagnosis of dementia, I respected his wish not to discuss his experiences using this term, and once again reassured him that the study was inclusive of people with memory difficulties as well as those with dementia.

Throughout the data collection period I found that issues relating to participants self-identifying as not having the diagnosis of dementia and the use of terminology which might be perceived as stigmatising in the participants’ paperwork were bound up with the matters of informed consent. As discussed above in section 1.3., I approached consent as requiring continuous negotiation and reaffirmation. By the time I met with research participants to conduct an interview they had heard about me and the study from befrienders, members of staff or carers and some of them had seen information sheets and were aware of the nature of their participation. Before each interview, I would discuss the person’s participation in the study and, following recommendations proposed by Cridland et al (2016), I would go through the information in the participant paperwork with the person verbally. These discussions led to questions from participants and provided space and time for me to clarify anything that concerned the respondents. The plain language conversations were instrumental for building rapport and getting to know my interviewees. Whether the person self-identified as not experiencing any memory problems, or accepted that they have dementia usually became clear during these informal pre-interview warm-up discussions.

I was also often interrogated before I even started the interview about where I’m from, how I came to the country and stayed. I felt I had to manage boundaries and disclose carefully only what I felt comfortable with. The interview dynamic were reversed with ‘the questioner becoming the questioned’ (Wilkinson, 2002: 169)

All interviews lasted between 45 minutes and 1.5 hours. I often felt that I was providing much needed company to the interviewees with some interviews lasting for over 2 hours, as the person would talk about other aspects of his or her life, including hobbies, past work, personal history. Most interviews were carried out on a one-to-one basis, with only one conducted with a dyad of a carer – person with dementia. Cridland et al, (2016: 1778) state that it may be helpful to conduct joint or “dyad” interviews with the person with dementia and their carer, as the carer may be able to provide prompts for the person with dementia and/or clarify things the participant has mentioned. However, I preferred to conduct the interviews separately with people with dementia and carers for a number of reasons: firstly, I wanted to hear the person’s voice without the carers’ prompts and to have a frank discussion which would have been more difficult to achieve if a carer were present. Secondly, some people with dementia I interviewed lived alone.

4.4.6 Interviews with staff, professionals, technology developers

For the interviews with staff, professionals and technology developers, a set of open-ended questions, and one closed question, were drawn up after reviewing the literature. An interview schedule was compiled from these, covering the topics of: pathways to care, expectations of care, experience with the service, and evaluation of the service. The interview schedule was piloted and then refined iteratively as fieldwork progressed (Willis et al, 2009: 28). Each participant was invited to review their transcript. For the interviews with system leaders, I followed Edwards and Holland’s (2013) recommendations of asking blunt questions of powerful interviewees such as the policy makers and challenging any evasive answers. Both age and gender play important parts in this ‘interviewing up’, and being a young woman, for example, can also result in older male participants wanting to exercise control and exert power. When interviewing NHS/CCG stakeholders, I asked what I felt were controversial questions - such as those relating to the higher cost of technology against the lower costs of care provided by human carers. Such questions elicited much discussion because the dominant discourse was that technology was being introduced to reduce the costs. Important to note, however, is that many respondents who are speaking in a professional capacity are likely to give the ‘official line’ and also be restricted by rules relating to corporate reputation, company disclosure policies and loyalty to the company or organisation (Fitz and Halpin, 1994; Edwards and Holland, 2013).

In the interviews with members of staff at case partner organisation, interview location also was significant. The interviews often took place within the organisation, even though we were in a private room that I had booked in advance. Some members of staff took longer to open up as they were worried about saying something wrong and this having an impact on their job. Half-way through the interview they would begin expressing own opinion and not sound like the organisation’s marketing brochure. Often saying ‘it’s my opinion’, ‘that’s what I think’ or‘Are you asking for my personal opinion or my view as a member of staff?’. Here, the aforementioned issue of only partial disclosure in light of an individual’s employer was overcome by respondents making a clear verbal distinction between their own opinion and that which they presented as a ‘professional’.

4.5. Obtaining Ethics Committee’s clearance

In order to carry out research which involved human participants, two ethical approvals were obtained from the University’s Research Ethics Committee – an expedited review and a full review. The application for the expedited review did not cover any research activities which involved contact with people with dementia, carers, volunteer befrienders or other groups considered vulnerable. The application was submitted for research activity with staff employed by the case Partner’s Befriending Scheme, technology developers, organisers of local dementia support networks, staff employed by the local Clinical Commissioning Group (the CCG) and other stakeholders. Research activities covered by the application for the expedited review included semi-structured interviews and participant observations at meetings. The details dealing with the issues of written informed consent, voluntary participation in research, the right to withdraw and data confidentiality were outlined in the participants’ information sheets and consent forms (Appendices 6 - 12). I identified two areas of potential risk – the collection and publication of potentially commercially sensitive data through interviews with technology developers, and a minimal risk to the researcher presented by lone working. The former was mitigated by the adherence to the principles of confidentiality, such as anonymization of data, secure storage and the checking over of interview transcripts by participants for accuracy. Other steps undertaken as part of the ‘procedural ethics’ preparation (Guillemin and Gillam, 2004: 263) included undergoing a Disclosure and Barring Service (DBS) check and completing training on the safeguarding of vulnerable adults and children, lone working and confidentiality provided by the case partner organisation.

As with all research that involves humans, it was necessary for me to address ethical concerns at the outset of the research process so that ethical research practice could be embedded in all research activity (Guillemin and Gillam, 2004). The completion of the ethics application form, design of research questions, information sheets and consent forms for participants and other ‘procedural ethics’ related activity did not immediately equip me with a comprehensive guide to ‘the unpredictable nature of qualitative research’ (Orb, Eisenhauer and Wynaden, 2001: 93). Nevertheless, considering potential risks and risk mitigation measures as part of the application process was a valuable exercise as I had to reflect on my own integrity as a researcher. It also highlighted to me the importance of following the fundamental principles of ethics in research such as respect for autonomy and prevention of harm (Guillemin and Gillam, 2004).

While conducting research with people who were not identified as vulnerable – technology developers, staff and managers at the Befriending Scheme and other professionals I was faced with a number of unexpected ethical issues. Guillemin and Gillam (2004) describe such issues as ‘ethically important moments’, ‘often subtle and usually unpredictable situations’ (2004: 262). For instance, in the course of a semi-structured interview exploring themes around dementia services design and delivery with a senior manager from a key social care organisation, the interviewee told me about her own experiences of caring for a parent living with dementia. Her emotional account of challenges, difficult as well as happy times, and changes in her parent’s memory, cognitive abilities and behaviour triggered painful experiences and she became upset. I faced a choice of whether to continue with the research activity or to stop the interview. I asked my interviewee whether she wanted to stop and gently reminded her, that she had the right to withdraw from the study, as outlined in the participant information sheet. She chose to continue with the interview. This situation illustrated to me the dynamic nature of informed consent which requires a ‘continuous renegotiation’, and of my participants’ right as autonomous persons to refuse to participate in the study (Orb, Eisenhauer and Wynaden, 2001: 95). When a similar situation arose during another interview focused on technologies and dementia care with a professional from a local HNS body who is also a carer for his parent with dementia, I was better prepared for it. Both events have also highlighted to me the importance of sharing the results of my research with people who shared with me very personal experiences which sometimes evoked painful memories.

The issue of informed consent became particularly pertinent in the course of the completion of the second ethics application for a submission to the University's full Ethics Committee. Initially, I was guided by the understanding of the capacity to consent developed by the case partner organisation running the Dementia Befriending Scheme. The Scheme links the capacity of the person to consent to receive its services to the person's ability to maintain personal care. As it is outside of the role of a volunteer befriender to provide personal care, the Scheme refers people with dementia who cannot perform own personal care on to other relevant services either within the organisation or to other social care providers. Upon reflection, I elected not to use this criterion for capacity assessment as I believe capacity to consent to participation in research or to accept a befriending or another service must not be contingent on an individual's ability to perform personal care. Instead, I followed the core principles of the Mental Capacity Act 2005 which apply to issues of capacity in research (Warner et al, 2008). My focus was on the first two principles in particular:

> *1. 'People must be assumed to have capacity unless it is established that they lack capacity.*
> *2. Before treating people as unable to make a decision, all practicable steps to help them do so must be tried'* (The Stationery Office, 2005:1).

Expanding the first point, it is necessary to explore how capacity or lack of it is established in relation to the diagnosis of dementia. Diagnostic procedures when dementia is suspected, according to Wind et al (1997), usually include a cognitive test called a Mini-Mental State Examination (MMSE). The authors point out that the test is particularly useful 'in cases involving uncertainty, denial of memory problems and an unfounded fear of dementia' (Wind et al, 1997: 102). The majority of service users supported by the Befriending Scheme have the diagnosis of dementia, and a number of my research participants underwent the MMSE. A number of scholars agree that MMSE and other cognitive tests alone are not sufficient for the diagnosis of dementia, which should also include the overall clinical picture of the person (Wind et al, 1997; Warner and Nomani, 2008). Neither cognitive testing is regarded as sufficient for the assessment of capacity (Warner et al, 2008) and should not be seen as 'a gold standard' for capacity determination as clinical judgements can often be 'unreliable and even invalid' (Moye and Marson, 2007: 9). Applying these conclusions to research practice with people with dementia, Warner et al (2008) advise researchers to be aware of the 'element of subjectivity' present in capacity assessments and to adapt their methods to the 'unique intelligence and communication skills of the individual before them' (Warner et al, 2008: 170).

Having outlined my approach to determining capacity to consent to research in the enhanced ethics application, I reflected on how to implement the principles of the Mental Capacity Act and recommendations from literature in my research practice. Looking for practical solutions, I turned to the second principle of the Act (2005), which mentions taking 'all practicable steps' to enable the person to make an informed decision (The Stationery Office, 2005:1). The notion of the 'informed decision' contained within the Act is closely linked to communication: if the person can understand, retain, assess and use information relevant to the decision, and communicate his or her decision by any means, the person is considered to be able to make own decisions (The Stationery Office, 2005:2). Taking these points as a guide for a better communication with research participants, I tailored my research tools - participant information sheets, consent forms, and interview questions to the communication needs of my research participants. For example, all printed materials had a larger font size, I used short focused sentences and short paragraphs to describe aims of the study and the nature of participation. I sought opinions of people living with dementia, carers and befrienders on the design and contents of the research tools, particularly on whether information presented was clear, and whether the layout of the documents made them easier to read. I amended the materials in line with the participants' comments. I was aware that research paperwork might be seen as a 'further burden' by research participants classed as 'vulnerable' and feeling already ‘burdened’ by cognitive challenges presented by dementia (Orb, Eisenhauer and Wynaden, 2001: 96). By involving research participants in the design and review of the research tools I attempted to embed the ethical principle of justice in my research practice, and to enable individuals with dementia to make informed decisions themselves (Wong et al, 2000).

Another issue relevant to the discussion of capacity and informed consent that was necessary to consider in the ethics application and the research practice was the fluctuating nature of capacity, where the ability to make informed decisions may change over time (Warner et al, 2008). Dementia research ethics studies warn against obtaining consent only at the start of the project, as participants may subsequently lose or gain capacity to consent (Warner and Noumani, 2008; Hubbard, Downs and Tester, 2003; Cridland et al, 2016). I therefore considered consent gathering to be an ongoing continuous process, renegotiated and reaffirmed at all stages of the participation (Cridland et al, 2016). I included a clear statement in the participant information sheet and the consent form emphasising that participation in research was voluntary, and that should the person withdraw his/her consent at any stage of the project, their participation would end immediately. During the data collection activities this principle was tested in practice, when on one occasion I indeed had to stop an interview when a respondent withdrew her consent to continue to take part in the research.

Assessing potential risks presented by the research to research participants with dementia and outlining the ways of mitigating them, I found myself in agreement with Guillemin and Gillam (2004) who commented on the subtlety of potential harms in social research and the difficulties in specifying and predicting them. In the ethics application the potential risks I described related to the inconvenience caused by my presence as a researcher in people’s private spaces and the upset and distress arising from some of the interviews questions. I also identified a mild potential risk to the researcher presented by the lone working. My mitigating strategies included clear communication with research participants with dementia and carers, where appropriate, in advance of the research activities, allowing some time prior to interviews for building rapport (Lloyd, Gatherer and Kalcy, 2006), a continuous negotiation and reaffirmation of consent to participate, and being guided in my interactions by the training around dementia I received from the case partner. In addition, I undertook training in Lone Working and Safeguarding Vulnerable Adults.

4.6. Positionality and personal reflexivity: managing multiple identities

In the course of my field work, juggling a number of roles became essential for building good rapport with study participants (Lavis, 2010). According to Cridland et al (2016), qualitative researchers conducting interviews often have to ‘negotiate multiple roles’ as well as draw clear boundaries around these roles so that ‘role confusion’ is avoided (Cridland et al, 2016: 1780). Some of my previous roles - such as being a former member of staff and a volunteer befriender with the case partner organisation - were beneficial for developing relationships with staff and volunteers in the Befriending Scheme, some of whom already knew me. Many of the challenges experienced by researchers who are complete outsiders - such as gaining access to research participants, negotiating with gate keepers, and so on - did not appear in the course of my data collection activities. However, being a familiar face to the scheme’s service users, carers and volunteers created other challenges, such as the lack of clarity around my role among the potential research participants. In order to avoid the boundary confusion and maintain an ethical approach in my research practice, I had to exclude a number of potential study participants from the sample, among them my former befriendees with dementia and their family carers.

Discussing the researcher identity within qualitative research interviewing, Lavis (2010) suggests that the facilitation of successful interviewing may include either ‘playing down the researcher’ with participants who may feel less powerful than the researcher and therefore apprehensive about the interview, and ‘researching up’ with, for instance, representatives of elites (Lavis, 2010: 321; 322). When conducting in-depth interviews, I felt that adopting and performing a number of identities available to me was instrumental for creating an atmosphere in which the research participants’ experiences were elicited and discussed with ease. During interviews with volunteer befrienders, carers and people with dementia, I emphasised my previous befriending role, with the result that members of staff seemed comfortable to engage in frank discussions with me because they perceived me as a former member of staff, their colleague. I 'researched up' (Lavis, 2010:322) with staff members employed by commissioner bodies and health and social care providers by performing an identity of a professional researcher with a career in social care delivery. Interviews with technology developers were facilitated by my previous experiences of using digital products they had designed which I trialled during my befriending visits with people with dementia. Although I attempted to be very clear about my role as a researcher, in some instances 'boundary confusion' arose in a number of encounters with participants (Cridland et al, 2016: 1781). My role as a postgraduate researcher conducting a study at a university put me firmly into the 'professional' bracket which resulted in some respondents feeling apprehensive and anxious before the interview. For instance, one of the respondents with an early stage of dementia was very concerned that his driving license would be revoked because of the diagnosis. Although the person and his carer had agreed to take part in the study and read the participant information sheet they picked up from the office of the Befriending Scheme, upon my arrival at their house I was told by the carer that her husband felt anxious about talking to me. He was concerned that I was there to test his driving skills. Before the interview could begin I spent some time talking about my role to the individual and reassuring him that I was not from the DVLA, and that the purpose of my visit was not at all related to testing his driving abilities. We discussed his participation in detail and went through the information sheet and the consent form together. The topic of driving arose a number of times in the course of the interview and afterwards, when the participant offered to drive me to the train station. It seemed that even after the reassurances I had offered the role confusion persisted; my perceived status of a professional visitor appeared to influence 'the image of self' that the interviewee presented – that of a competent driver with many years of experience (Nygard, 2006: 105).

Another example of boundary confusion that I encountered in the field was in relation to the role of a professional researcher – something that was present throughout my interactions with a group of older people attending a luncheon club. I was invited by the group's coordinator to meet the attendees of the club and to speak about my research in front of the group. Although I mentioned my befriending background, and some of the attendees knew me as a befriender, my presentation - that touched upon dementia prevalence statistics, the need for the type of research I'm conducting, and the anticipated contribution the study would make to dementia care practices - resulted in the club members' perception of me as someone who is an expert in dementia diagnosis and care. I became known as 'the doctor woman'.. It was not my intention to introduce this identity into my interactions with interviewees, and I was unwilling to perform it in the field (Lavis, 2010). When, during interviews, I was asked for advice relating to the Mini Mental State Examinations (MMSE) – whether there was a 'pass score', and whether it was possible to 'pass' or 'fail' such an exam -I was wary about taking on an advisory role (Cridland et al, 2016). In these instances I clarified my role and stressed that despite being known as 'the doctor woman' I was not medically trained and could not offer an opinion or advice on memory testing.

In the course of the field work, in particular during in-depth interviews, I could sense what Lavis (2010) termed 'disingenuity' resulting from me adopting and performing a number of research identities. At times, it was clear that these led to role confusion, with me having to adapt to new roles assigned to me by research participants (Lavis, 2010: 328). The tensions that arise when the researcher has to juggle and manage a number of roles and identities, according to Lavis (2010), can have a positive impact on the development of a research practice characterised by integrity and skill, demonstrated in the ability to tailor data collection activities to the individual needs of participants. In my own research practice, I was compelled to adopt and practice a variety of roles not because I felt it would enable me to simply extract as much data from my research participants as possible, but because I was enmeshed in often complex encounters permeated by power inequalities between the researcher and the researched (see also Orb, Eisenhauer and Wynaden, 2001).

4.7. Engaging with power dynamics

According to Wilkinson (2002), power dynamics present within a research relationship with people with dementia can reflect power inequalities faced by older people in society in general, such as being marginalised through ageism and experiencing stigma associated with dementia. The author calls for researchers to recognise and be mindful of these asymmetries in research design and choice of methods (Wilkinson, 2002). Illuminating the interrelationships between identity, power, space and place, Edwards and Holland (2013) emphasise that complex patterns of power between the researcher and the researched are created when identities, whose aspects include ‘positions in hierarchies of gender, class, age, ethnicity’ are played out in particular places (Edwards and Holland, 2013: 44). Thapar-Bjorkert and Henry (2004) challenge the dualistic, top-down models of interaction between study participants and researcher, in which the former is defined as powerless and ‘oppressed’, and the latter – as a powerful ‘oppressor’ (Thapar-Bjorkert and Henry, 2004: 364). Theorising power as ‘shifting’, ‘intersecting’ and ‘dispersed’ among parties involved in the study, the scholars conclude that often it is the researcher who experiences exploitation and manipulation, particularly if the researcher is seen as being outside of the dominant group or culture (Thapar-Bjorkert and Henry, 2004: 364). Throughout my field work, I was regularly reminded of my own less powerful position in relation to the interviewees. For example, when seeking permission to attend befrienders’ forums and coffee mornings for carers, I was in return asked to help with the event organisation, including doing grocery shopping, setting up the room and equipment, and clearing up afterwards. I was often introduced to service users by the scheme manager as ‘a student on placement’ within the organisation, which conferred on me a role of a junior ‘knowledge seeker’ (Edwards and Holland, 2013: 78). This contrasted with a more powerful identity of the ‘doctor woman’ assigned to me by participants with dementia whom I interviewed at the luncheon club. My status of a younger student researcher interviewing older people often exposed me to the necessity to negotiate the age differences in order to achieve an atmosphere of trust and collaboration between the younger interviewer and an older interviewee (Tarrant, 2014). For me, it was not always a straightforward undertaking and usually the first few minutes of the interview were taken up by me ‘adjusting’ to the dynamics of the conversation. According to Tarrant (2014), older age is a fluid stage in one’s life, with individuals adopting a range of identities. During the interviews, I felt that at times my older participants adopted an identity of a ‘parent’ and viewed me as a ‘daughter’ rather than a professional researcher. On one occasion, I was asked to stop the interview by an older female participant who said that I simply ‘didn’t understand’ what being older is like.

4.8. Data analysis

The data was gathered from a variety of sources through the use of qualitative methods. These included in-depth qualitative interviews, direct observations and documentary evidence from interactive workshops presented and allowed a rich and complex picture to be developed, and gave an array of insights into the phenomena under study. In the analysis process, performed across the units or ‘across case’ (Baxter and Jack, 2008: 550), the data strands were converged rather than considered individually. This approach to analysis, according to Baxter and Jack (2008), makes the findings more robust and contributes to an in-depth understanding of the whole phenomenon.

The data from both interviews and observations were subject to a thematic analysis using NVIVO 10 data analysis software (Greg, Bunce and Johnson, 2006). Before the process of coding could begin, and consistent with grounded theory (Hulko, 2009), I prepared the data by transcribing the interviews. In total, 41 transcribed interviews, and observations notes from two separate observations were prepared for analysis and imported into NVivo 10 data analysis software. Other preparatory activities that I carried out included: reading the transcripts repeatedly to gain an overview of the data gathered; studying the observational notes and writing memos; making lists of emerging recurrent themes. I followed with steps outlined in the ‘framework approach’ (Ritchie and Spencer, 2002: 2) – an analytic approach employed in applied policy research. This approach to qualitative data analysis enables the researcher to systematise the ‘unstructured and unwieldy’ material collected through qualitative methods (Ritchie and Spencer, 2002: 5) by following a set of well-defined interconnected stages. After I completed the data preparation and familiarisation stages described above, I identified key recurrent themes arising from the interviews and created nodes or ‘containers for each topic’ (Bazeley and Richards, 2000: 3) in the NVivo 10 programme I used for data analysis. I then proceeded with coding each interview transcript ‘in vivo’ or live (Bazeley and Richards, 2000: 3) and saving segments of text into the nodes. In total, I developed 251 nodes, some of which contained codes relating to a single group of research participants, for example the node ‘Befrienders’ [opinions] on place’, while others spanned a number of participants’ groups, such as ‘Gendered nature of care’, ‘Driving with dementia’ and ‘Monitoring and surveillance through technologies’. While coding the interviews ‘in vivo’ I created notes and memos both within the software package and hand-written, outlining and charting the relationships between the themes. I found myself reflecting on the initially developed thematic framework and returning to the original key themes and categories, which I re-grouped and redefined. The flexibility of the framework approach allowed me to interrogate my data in a way described by Bazeley and Richards as ‘non-linear’ (2000: 12), and I often was able to determine the salience of key concepts and connections between them by reviewing my notes and memos, repeatedly immersing myself in the data and relying on my intuition. As a result, I developed a complex database with reviewed and regrouped codes contained within nodes or key themes, which I was able to aggregate into meta-themes through identifying patterns in the responses and finding associations among the respondents’ attitudes towards the phenomena discussed during the interviews. I will discuss the reviewed meta-themes drawn from the analysis in detail in chapters Five, Six and Seven.

4.9. Concluding remarks

In this chapter, I have discussed the qualitative case study approach to researching a set of complex interrelationships between ageing in place and living with memory loss while being supported and cared for by unpaid family members and volunteers at the time when everyday life is becoming increasingly technologized. The case study approach has been instrumental to the illumination of the multiple and diverse care practices and ageing strategies developed by the participants, while keeping the focus of the research contained within a bounded context. I shall present the findings of the study within subsequent three chapters: chapter Five presents the participants’ views on what constitutes care and the dispersal of responsibilities for caring for family members between public and private care providers, family members and volunteers. I also discuss the implications of these expectations and the impact of the responsibilisation on family carers. In chapter Six, I discuss the interrelations between ageing and place by drawing on the participants’ views on the meaning of place to older people living with dementia and their carers, and the resulting impact of ageing in place on personal autonomy. Chapter Seven is dedicated to a detailed exploration of the respondents’ perspectives on care supported by the use of ‘assistive technologies’, both digital and analogue. It also presents findings relating to the adoption and abandonment of technologies, as well as factors promoting or hindering its use by older people.

Chapter Five: Care: whose responsibility?

5.1. Introduction

In this chapter, I examine the understandings of professionals, family carers and people who receive care of the responsibility for the care of people living with dementia. At the opening of section 5.2. I trace the trajectory of professionals' views which reflect the shift of care provision from institutions to community settings. I argue that the resulting official discourse calls for reorganisation of care delivery with the increasing share of responsibility shouldered by family members, community and volunteers. The impact of the changes to the organisation and public funding to care provision on lives of family carers is explored in section 5.3. In doing so, I seek to contribute to geographical literature on shifting landscapes of care with attention to dementia care practices in Liverpool and North Wales. Section 5.4. explores the views of people with dementia in personal autonomy and independence and presents examples of how these are practiced in their daily lives. In section 5.5. I outline the approach taken by the befriending scheme run by the partner organisation to matching befriendees to volunteer befrienders and explore the how such relationship develop over time. Section 5.6. concludes the chapter.

5.2. Competing understandings of responsibility for care: views from family carers and professionals

Interviews with family carers, front-line and management staff at the case partner and local health and care commissioners carried out in the course of this study reveal a number of competing perspectives held by the respondents on responsibilities of family carers for care of those living with dementia. This section examines and contrasts views of 'professional' respondents to those of family carers on a range of aspects relating to caring for a family member with dementia. The purpose of comparing the respondents' views is twofold: firstly, an exploration of convergences and differences in the opinions is helpful for elucidating how professionals and family carers construct what constitutes 'care'; secondly, this comparison may offer insight into how these understanding of care shape actual support of people living with dementia – by family members within the home, and by professionals involved in the commissioning of social care provision. It must be noted, that although often in the course of the interviews the professionals' responses related to the health and social care systems in general, rather than dementia care at home, their quotes are included below as they reflect the respondents' judgements about what 'good care' should entail, whether delivered at home or in a hospital setting.

In the interviews the professionals were asked to talk about relatively recent transformations in health and social care, which in England manifested in the shift from publicly funded services provided by the state to pluralism in social care provision, including community-based care services delivered by voluntary organisations and families (see for example Wiles, 2003; Milligan et al, 2007; Milligan and Wiles, 2010). A number of scholars (see Lawson, 2007) have argued, that one of the outcomes of this transformation is the reframing of responsibility for care, characterised by the emergence of government policies impelling individuals and families to take greater responsibility for own health and care in order to prevent their perceived over-reliance on public services and to encourage a greater commitment to self-care. This was something referred to in the interviews:

> *[…] I don't believe that the state is best at providing all aspects of [care] delivery. I think there are certain things that you need Third Sector, private sector but increasingly civil society, us as citizens, need to be given that responsibility because that's the other challenge that we've had and why we are where we are, in my mind.* (TS, CCG)

The interviews reveal that professionals interviewed for this study commonly reproduced the discourse of what Lawson (2007: 5) refers to as a 'privatised responsibility' for care, placing this responsibility in part on the families of people who need care, and in part on the voluntary sector. This view was also echoed by the representatives of voluntary care provider organisations. For example, UJ, a Head of Services at the case partner organisation with responsibilities for managing front-line staff explained:

> *'But at the same time you have to take personal responsibility and I believe that self-care should be sung from the rooftops, stressed every day how important it is*

> *and stop being passive recipients 'Oh, I'm ill, that's it, I give up, I'm going to rely on the NHS from now until the end of time.'* (UJ, Head of Services)

A key finding from the research, therefore, is that what the previous literature (e.g. Lawson, 2007) noted as an emerging policy change has now become well embedded in the discourse and practice at the state and third sector level. An important finding, however, is that this view was not shared by family carers:

> *'We then moved into a position where as practitioners I don't think we say enough, you know, 'OK then, so you need a care package, so as a family what are you going to do to support mum or dad in that care package?'* (TS, CCG)

TS's quote highlights the newly emerging interaction between the state and family carers, where families are directly asked what contribution they are going to make toward the care needed. What can be seen from the analysis of professionals' responses, is that this refutation of 'privatised responsibility' was multi-layered, with some thought to show an unwillingness to dedicate more of their time to the person they care for and others demonstrating a refusal to co-deliver care in collaboration with social services. For instance, a senior member of the team from a health and care services commissioning body indicated that the over-reliance on statutory provision has its roots in the original design of the National Health Service established to respond to health needs rather than to promote self-reliance and self-care:

> *'Yes we do stuff to people, we don't enable people to do things themselves, and that's 50 years of provision that's got us to this point. And probably 50 years of investment that hasn't been smart investment.'* (TS, CCG)

According to TS, the widespread expectations, amongst citizens, for universal support from health and social care services have shaped attitudes among recipients of health and social care services marked by helplessness and inertia:

> *'That challenge then translates into a citizen expectation of what they get from the NHS and care services, 'They will do things to me rather than enable me to do things for meself [sic] and me [sic] family.' So that [is] a common-sense view [that]*

> *when you require care and health services the state's going to wrap a big blanket around you and give you a cuddle and make sure you are alright.'* (TS, CCG)

TS's view was echoed by a senior member of staff at the case partner organisation – provide of social care and support to people with dementia, who highlighted and critiqued 'a culture' of over-reliance on publicly funded services:

> *'I think that if self-care is done correctly it can be massive. I acknowledge that there is a certain percentage of the population that aren't interested in self-care, don't want to, they are quite happy going to the doctor, being told what to do, being prescribed medication, going away and doing that. But I think self-care is massive, that people … need to get out of this culture of being spoon-fed.'* (UJ, Head of Services)
>
> *'So I'm a social worker and I'm visiting somebody who has dementia to ensure that their support needs are fulfilled, but actually if they're isolated what can I do, what conversations can I have with the family to say 'Mum could really do with seeing you and other kids every year a bit more often, how are you going to do that?'* (TS, CCG)

Taken together, these extracts illustrate strong support for to the move toward privatised responsibility for care in the eyes of professionals. Their interviews suggested a strong feeling that people with dementia and their carers had become passively 'spoon fed' via the NHS, and did not seek to provide for themselves. The outcome of this was for many professionals to report taking a more paternalistic approach to care in their discussions with families – seeing it as their responsibility to make them aware of the importance of providing care outside of publicly-funded social care system.

While the discourse of urging individuals to take greater responsibility for own health and wellbeing appeared to be shared by most professionals, the interviews suggested that its application to social care was more complex issue. For example, MT a front-line service manager at the case partner organisation recognised that while 'messages' about preventing ill health through behaviour changes such as quitting smoking are unambiguous, their relevance within the context of social care is not sharply defined:

> *‘Again I think it’s just historical, isn’t it, that if you’re sick it’s somebody else’s responsibility to fix that. Or if you, for example, it’s all preventable, preventable health, so smoking for example, I think more people now are taking responsibility for stopping smoking because the messages around the dangers of smoking are much more, everyone’s aware of those. And people have taken more responsibility and are saying ‘Well actually no, if I smoke I’m going to get sick’. So it’s a very complex one I would say, it’s like how do you get those messages out in terms of taking responsibility for care needs as well?’* (MT, Service Manager)

The quote highlights the fundamental challenge that many professionals faced in how to articulate the practical application of privatised responsibility. MT’s choice of example here is telling and highlights a potential challenge of applying this general model to the specific case of dementia. They use the oft-cited examples of diabetes and smoking, where the connection between ‘self-care’ and health benefits are clear whereas dementia is not as easily targeted to one health behaviour or preventative lifestyle practices. In the absence of a clear articulation for dementia, most of the professionals resorted to extolling the virtues of technologically in supporting dementia care:

> *‘The goal for all of this was about how do we get people to do more things for themselves and their families, applying technology just helps you to do that quicker, faster and at greater scale. And that’s what the [programme] was about, taking great technology things and helping the self-care, the self- management and the self-service agenda in care, in health to move forward at pace.’* (TS, CCG)

What is apparent here is a conflation of technology and autonomy. Rather than addressing the perceived underlying resistance to privatised responsibility, there was somewhat of ‘black-boxing’ whereby professionals suggested that technology offered a catch-all solution.

Although I discuss the role of assistive technologies in dementia care in detail in chapter Seven, the quotes from professionals relating to assistive technologies are included here for the purposes of exploring the discourses of self-reliance and autonomy furthered by representatives of organisations working within the areas of social care commissioning and provision. Practical suggestions on urging family carers ‘to do more’ for care recipients stretched further than simply ‘having conversations’ or promoting ‘messages’ of self-reliance, with some care providers raising the possibility of family carers making greater financial contributions to the costs of care rather than relying on ‘freebies’ provided by local authorities:

> *‘And then technologies [are] then that desirable that person will then go out and purchase it for themselves instead of it just being a freebie given by the council because you’ve got a high level of need. It’s just trying to change that culture of when we’re in need relying on services to support us, and like flipping that on the head and saying ‘Well actually we can be doing a lot more for ourselves if we knew that technology was out there, and if it was affordable’.* (MT, Service Manager)

This can be seen as a micro-scale commodification of the care process – i.e. not presented as free advice, but as a service/technology to be bought. Moreover, messages around ‘cost cutting’ and ‘saving costs to the NHS and social care’ were a recurrent theme within professionals’ perspectives:

> *‘I mean the costs of the NHS now compared with when it was set up 60 years ago, 70, you know, obviously there’s an ever-growing demand and therefore to have people take more responsibility for their health, be able to research some things online, be able to contact their GP, be able to make an appointment online, all those things have a benefit in terms of the cost of providing the service.’* (RL, Digital Inclusion Coordinator)

This is in direct contrast to the perception that some carers hold about their role, their daily challenges and the lack of publicly funded support available to them, including lack of practical support from the social services, the length of time it takes to contact a social worker, poor quality of care provided by agencies and so on.

This discourse of self-reliance was often framed by professionals as a conversation about citizens’ ‘empowerment’ and ‘rights’ rather than a necessity to be implemented in order to cut costs of publicly funded services, as the quote below demonstrates:

> *‘Not enough of those conversations are happening because we don’t see patients, service users as citizens who’ve got a voice. We disempower them, we disable*

> *them by the service that we put round them because that's the service model that we operate now. Doing stuff to people rather than enabling people do stuff themselves.'* (TS, CCG)

While the professional' ideas about 'empowerment' and 'rights' were often accompanied by statements about taking personal responsibility for own health and wellbeing, this study has found that little was said about mechanisms that could support people receiving dementia care to meaningfully participate in decision-making processes and to be able to have control over resources. These elements, according to Castro et al (2016), are defining attributes of patient-empowerment. The concept of care recipients' empowerment in the context of living with dementia can be thus studied further for the purpose of elucidation of the understanding of empowerment between different groups.

Some professionals felt that people whose health may be seen as poor are partially or wholly responsible for letting it deteriorate either through bad lifestyle choices or through apathy and a lack of interest in positive interventions and in ways to prevent illness:

> *'…type 2 diabetes by being responsible for your lifestyle, so you can self-care at that point, you know, exercise, eat right, don't smoke, all of those virtuous things that we should all do. But there's that so we need to take that personal responsibility and then if we're at risk of we should also then take responsibility of finding out what can I do to prevent this?'* (UJ, Head of Services).

Some of the respondents believed that taking responsibility for monitoring own vital signs such as pulse and blood pressure through the use of technology and the Internet would alleviate the pressure placed on health services and result in fewer visits to medical professionals:

> *'I mean the NHS is, you know, a 21st century organisation moving ahead in terms of sort of some high-tech care and pushing towards being more independent and taking more responsibility for their health whether that's in terms of having access to finding out about health through the internet in the general sense, or whether it's more specific about being able to take your own blood pressure and kind of email*

> *that into your doctor on a daily basis to save you going and clogging up the GP's surgery and all those things.'* (RL, Digital Inclusion Coordinator).

Thus, the idea of technologically supported, pro-active and informed self-care was seen by these interviewees as not only a cost-saving undertaking but also as a right moral choice that everyone should attempt to adopt. Those failing to self-care or to care for family members effectively were regarded as a burden on limited public resources.

In contrast to the professionals' arguments, carers felt that they were already doing as much as they possibly could without relying on any support from statutory agencies. Firstly, rather than relying on the social services to source care agencies and organise visits, family carers took these administrative and coordinating tasks upon themselves. Although family carers are often referred to as 'informal carers' (Kirk and Glendinning, 1998: 370; Greenwood et al, 2018: 40), the in-depth interviews revealed that a significant amount of carers' time was spent organising and coordinating care arrangements for the family member with dementia. Tasks undertaken were varied in nature, and included contracting and financing the delivery of personal care through private agencies, arranging hospital appointments, mobilising informal social networks constituted of family members, friends and acquaintances to make regular telephone calls and visits to the person with dementia and so on.

> *'I spend a lot of time kind of arranging visits and making sure that visits are cancelled and those sort of things, and adjusting the timing because they come in too early or come in too late, those sort of things, you know. It takes just an age really... I mean my parents live about three hours' drive away so actually… it's this logistical planning which is really difficult.'* (OL, carer for parent)

> *'I contribute towards it, you know, so I pay monthly, every month I pay £211 towards them [paid carers] coming to wash him [husband] every morning. And in the evening they come and take off his clothes and put on his pyjamas, that's all. Takes them 10 minutes, they are done and gone.'* (CA, carer for spouse)

> *'But it's more the appointments that get me down. I mean he had 3 appointments in one day a couple of weeks ago. And you're here and there, you know, you just feel…'* (V, carer for spouse)

> *'When I'd get to work I'd phone but he was capable of answering the phone then. 'Are you alright, D?' And I'd leave… certain things out so about half nine - ten o'clock I'd phone him 'Go and have your snack', and I'd leave him a cold drink because he couldn't access the kettle. Then [the daughter] would come in and make him a hot drink, and then I'd phone him at lunchtime 'Go and have your lunch, it's there,' so the lunch would be left so he'd have that. And then about half two – three I'd phone him 'Have a drink and there's fruit, go and eat the fruit. Right, I'll be home in just over an hour, I won't be long.' And that's what I was doing to keep him safe.'* (BR, carer for spouse)

These quotes pose a challenge to care provided by family members being described as 'informal'. Whilst there is no monetary or contractual exchange in such familial relations, the administrative burden arguably creates a formal task. In addition to ensuring that basic needs, including personal care, food and drink intake and safety of the family member with dementia were met and day-to-day care arrangements ran smoothly, family carers had to take responsibility for longer-term care and residential arrangements, such as identifying a suitable semi-independent sheltered scheme or other types of residential care, or negotiating financial assistance for care at home with social services. This type of organisational work was often done with little support from statutory services, reflecting the overall shift within the provision of social care – from publicly-funded services to individuals and families discussed in detail in chapter Two.

> *'When the Care Navigator came out we were going through care homes and I knew somebody who'd been in [care home]. So while she [Care Navigator] was there she just phoned to find out if they had any beds. And as I've said before, the manager was very helpful, so then when the Social Services rang up we could turn round and say 'Yes, we know there's a bed at CV'. So that was all set up. But then when they came out to do the assessment it wasn't nursing care my mother needed, it was residential. And they have another home in DL which is possible a 20 minute*

> *walk. Now, they didn't have a bed so never mind, she's kind of stuck with us, we'll look after her. So we took her to CV. My first impression was - I don't want to keep you here too long. And then I had to take a wheelchair back and this woman greets me at the door and says: 'You know she's here just for a fortnight, after that you'll have to sort something else…' We tried for respite in the early part of May and this home had a bed, and she'd had had a fall so that put paid to that. So at the back of my mind it was that. I'd made an appointment to go and see [care provider] in [road] and then went to [care home], and then I did [another care home], so I visited three'* (PD, carer for parent)
>
> *'But you know, I brought her [mother] down and … she just settled in my house, never asked to go back and stayed settled while I was… What I'd done because I'd been planning that, I'd been thinking before that so I got things in place like voluntary work and that, because I knew I'd be at work and I thought 'I don't want her sitting I the house all day on her own,' so I then had got her some voluntary work in place, so when she did come down she was able to start that pretty straight away.'* (WL, carer for parent)
>
> *'…you ring [statutory social care body] up who are basically an answering service, so you've got to leave a message. They've got to then email the social worker, and you've just got to wait for the social worker to get back to you. It wasn't, two or three weeks ago I thought the social worker that we've been allocated to worked four days on and four days off. We were actually going into residential care, and then she turned round and said 'I only work two days a week'. So everything was held up. When you expect, you ring your Social Worker up and someone would get back to you, but no, we had to wait until she came in'* (PD, carer for parent).

Together, these quotes represent a finding relating to a redefinition of what is seen as care. Whilst conventionally care is thought of as the actual doing of care, what is evident from the interviews is that the associated administration of care is a vital part of the overall care provision by family members.

As the above quotes from carers demonstrate, there was little reliance for support on statutory social care provision. This was the case for all family carers interviewed. The majority of carers had limited expectations with regards to publicly funded support or advice services and thus accepted that the responsibility for every aspect of care arrangements lay with the family. This lack of expectation around support extended to other state actors, such as social care services and health professionals as well as to private providers. Moreover, when carers recounted their experiences of seeking or receiving services and advice from statutory agencies, these services were often described as inadequate, overly bureaucratic and difficult to access:

> *'As I say, trying to get hold of a social worker is like trying to get hold of a needle in a haystack [laughs]. You don't have a direct contact with a social worker… I suppose they [social services] weren't coming in on a regular basis, the only people that were coming in on a regular basis were the person who got her up and the person that got her ready for bed, cos the likes of social services and the Occupational Therapist, you could be, well you could be waiting three years for them to come and visit you.*' (PD, carer for parent)

> *'And of course at present, which annoys me, he's only got a link worker, apparently, he hasn't got any social worker now. So that's not very good I don't think, but what can you do?'* (V, carer for spouse)

Support offered by private home care agencies received similarly negative feedback from family carers who highlighted paid carers' poor punctuality and organisation, a lack of continuity of service and overall concerns about the quality of care provided:

> *'I mean the company that we use isn't that bad but I went through a very bad patch actually when they weren't very good. It's kind of weird, and I don't know if it's a deliberate thing and it probably is, but I think the carer companies, they kind of stratify the care that they provide depending on the scale, they're maybe doing it subconsciously but I think they provide different people at different stages.'* (OL, carer for parent)

> *‘In the early days we were finding they are coming at half past eight to get her up, they couldn’t come in at ten o’clock. Then we got a girl, yeah, we thought we worked out a pattern, but then it seemed she only did Tuesday to Friday so on a Monday you were not sure who you were going to get. Saturday, two Saturdays on the run – quarter to twelve! The first time because I’d got her up, [I] got a phone call to say ‘The carer’s outside your door trying to get in’, and all I was doing was shouting down the phone ‘What good’s this at a quarter to twelve!?’* (PD, carer for parent)

> *‘Christmas before he went into hospital, that was the first time I’d had anyone to come in and help me. And that was to wash him down and put him in his pyjamas and that was it. So they should have come between half five and six o’clock, they could turn up any time from half four, half seven, half eight, nine o’clock. So you’re sitting on pins waiting for someone to come. And it’s not the idea, you just don’t want people coming and going cos it’s never the same person. So you don’t get to know them or they get to know you or [husband], you know. So there’s many a time I’ve had to leave them in the living room to wash him down with a bowl of water and go out. That’s not nice, you know, that’s just not nice at all.’* (BR, carer for spouse).

The combined lack of support from statutory services and a poor quality care delivered by paid home care agencies at times resulted in crisis situations forcing the family carer to call in the emergency services:

> *‘She’s [social worker] useless, absolutely useless, honest to god, she was useless. He [husband] got assessed in the day centre, wasn’t his consultant, a consultant sent an understudy. He was sent home to me, he was off the scale and they knew that, and they sent him back home to me. I ended up with ambulances, police because they tell you to ring the police. I don’t want the police, I want someone, there should be a unit of bodies who know how to deal with a man or a woman when they go off the scale through the dementia, but you have to get the police out.*

> *It’s not nice, is it? You know, he’s not a criminal, he’s never done anything wrong and there was a lot of trouble over that.’* (BR, carer for spouse)

As the above quotes demonstrate, overall, family carers had low expectations from statutory and private provides in relation to support with caring for the family member with dementia. They reported largely relying on own initiative and experience in identifying and arranging a suitable place to live for the person with dementia, drawing on personal financial resources to part-fund personal care and administering and coordinating visits from paid care agencies. These undertakings were additional to the daily care tasks that the majority of the family carers interviewed carried out themselves or with occasional support from other family members. Notably, most of the family carers identified as a sole carer, with limited support from family or friends, whether family was geographically proximate or distant. The carers’ reluctance to seek help from statutory services arose not from their belief it was not right to do so, but from their experiences of poor service, long waiting times and a poor quality of the services that were available.

5.3. Implications for the carer: familial duty, guilt, loneliness

Faced with the pressures explored in the above section, the carers often reported feelings of deep loneliness, social isolation, guilt, anxiety and physical exhaustion when asked to talk about what being a carer meant to them:

> *‘You become very lonely. It’s a very very lonely disease because people don’t come near you, friends, you know, they tend to run away from you more so than come and knock and see ‘Are you alright? Do you want a cup of tea? Is there shopping you need? Can we do anything?’ You’re on your own, you’re sitting on your own. And it’s not as though you can have a conversation, you can’t cos nothing makes sense. And then you’re constantly watching to make sure he [husband] is not doing anything he shouldn’t. He might sit for a while and then he might go on a rampage, or something silly, that you don’t even know what, will just flip him over. And you’ve just got to ride it out with him, basically. So you are very very lonely with this*

> *disease, very lonely. And there's no one for you to sort of say 'Oh can I come down?' You know, there's no one. Like the cancer have the Macmillan nurses, with this disease you're left on your own to sort everything out.'* (BR, carer for spouse)

In the excerpt above BR has described what can be seen as a twofold nature of social isolation that she has experienced - a decrease in the amount of social contact with friends and difficulties in communicating with her husband caused by the progression of dementia, which also affected her husband's behaviour:

> *'LO: So you wanted him to stay in his own home but it wasn't possible?*
> *BR: No. But then he started to get a bit violent and that didn't help.*
> *LO: The behaviour changed?*
> *BR: Oh yeah, yeah. You know, it was way out of character for him, you know.'* (BR, carer for spouse)

Often, in addition to coping with fast and profound changes in the behaviour of the person with dementia, and adjusting to reduced contact with friends and acquaintances, carers reported difficulties with being able to meet newly emerging health needs of the individual, as well as with own deteriorating physical wellbeing:

> *'It's [being a carer] getting, definitely getting harder. Certainly with this hearing business, cos I woke up this morning and I didn't have a voice because I'm having to shout at him [husband].'* (V, carer for spouse)
>
> *'Eventually we got people to come to help because my back, my back, well I did nursing for 34 years, and after nursing this is what I'm doing – looking after him [husband] now, so my back is hurting'.* (CA, carer for spouse)
>
> *'I do feel tired cos if I sit there now and nobody talks to me I'll just fall asleep, just now, within 2 minutes. I'm so tired, so the children keep telling me 'Go to sleep early', well I try to, you know, to do that after they come'.* (CA, carer for spouse)

Some carers connected the reduction in social contacts and resulting social isolation to the challenges of providing adequate personal care to the family member with dementia:

> *'You are battling with the kind of basic things around making sure people are fed, and making sure people are showered… And with kind of toileting difficulties thrown in as well, I mean you do get, it's really difficult, you do get socially isolated.'* (OL, carer for parent)

Being able to anticipate and attempting to meet diverse needs of the family member with dementia - from self-care prompts and reminders to personal care - placed an additional strain on the carers' mental wellbeing:

> *'And you think, this is a person that, the marriage is over 48 years we've been together, you know, you didn't think this could happen. You know helping your husband to wipe his bum, get him dressed, everything. I have to think for him.'* (CA, carer for spouse)
>
> *'I had to leave 4 different notes - remember this, remember to get his shave, remember to change your clothes - and all this, you see. Otherwise he wouldn't, he'd still be sitting there. That's what gets you down sometimes.'* (V, carer for spouse)

> *'Yeah, yeah and food as well. You know, what he used to eat he'd stop eating, didn't like it. And stuff he wouldn't eat he decided he'd like it. So it's hit and miss food wise. But you know, you are on your own, it's a very very lonely disease, very lonely'.* (BR, carer for spouse)

Another factor that affected some carers' mental and physical health was connected to juggling competing demands of caring for a parent with dementia and spending time with younger family. Carers, such as OL whose quote is presented below, are representatives of the so termed 'sandwich generation' (Riley and Bowen, 2005: 52) because they care for a parent or both parents and a child or children under 18 years old. Research into this generation of carers shows that their mental and physical health is particularly at risk of fast deterioration, and that they experience increased marital conflict and poor outcomes in their parenting activities (Riley and Bowen, 2005).

> *‘I’m sure there are some people who’ve got parents at the same stage as my mum and dad who are doing it all themselves, but it’s just emotionally and physically absolutely crippling. And also I’ve got to look after my wife and my daughter as well, you know, they need time as well, so it’s that sort of balancing act.’* (OL, carer for parent)

Having received limited to no support from employers, some carers who still participated in the labour force reported experiencing increased episodes of poor health and a deterioration in emotional resilience, including feelings of frustration, a sense of being let down and difficulties with managing one’s emotions:

> *‘Because I was, I’m sort of still in work, I’m off now, I’m off ill because I’ve had a situation in work, they won’t recognise me as a carer. And I had a rough Christmas because [husband] had had a suspected heart attack and I ended up ill with a chest infection.’* (BR, carer for spouse)
>
> *‘And I asked ‘Is there any chance I can have a day off, I’m rely struggling?’ ‘No’, that’s all I got ‘No’. Anyway I got through the Christmas and it all started over a locker key. And I lost it, I totally totally lost the plot. And it bothered me that these people who I work with could not give a monkey’s about me or my life, not that they need to but a little bit of support in the right places would have gone down enormously. But they don’t care. You feel like nobody cares about you and that’s a problem… My husband’s not their problem. And I thought that’s not the point, I’m your worker, I’m a good worker even if I say so meself [sic]. But they don’t appreciate workers.’* (BR, carer for spouse)

Mental health concerns reported by the majority of the carers taking part in the study ranged from feelings of anxiety triggered my minor crises interrupting daily care routines to cases of deep depression developed throughout the process of caring for the family member with dementia:

> *'Yeah, that's a worry because, we have to just come from across the road, that's all I have to come is across the road, I can do that extremely quickly, and I feel like it's not quick enough. So the fact that they're then responding I know it's a longer timeline and that is a worry because I think 'Well where could my mum have been in that time? You know she could have potentially wondered out the building, you know, so when it's like that that's very, it heightens your anxiety greatly, you know, you just think 'Oh gosh!'* (WL, carer for parent)

> *'So I don't know, just one day at a time that's all I do. I don't think of a future, it's just day to day. Christmas bothers me, I don't want it, I don't want to celebrate it but I have to because I've got grandchildren. Christmas shopping, I used to enjoy, I was always in town, always around town, I love town, shopping and stuff. Just got no love for anything at all. I've lost that, I don't know, just lost whatever it is, it's gone. I'm just not enjoying it. Me [sic] daughter will say 'Mum, do you want to come into town?' And I can't bear the thought of it because I can't bear to be with loads of people around me, can't cope with it. I'm not enjoying it, I'm not enjoying anything and I think it's because I'm missing him. I'm pining for him basically, that's what I'm doing.'* (BR, carer for spouse).

Notwithstanding the challenges experienced by the majority of the respondents, the carers reported drawing on a range of resources to ensure they were able to continue providing a high standard of care to the family member with dementia. Some maintained resilience by framing their carer role as driven by duty based on familial and spousal bonds:

> 'It [being a carer] means a lot to me because I look at it, well, we've been married now for, as I say, for 48 years. And when you get married for better or for worse, I say this is the worst time now. And it's my duty to care for him, you see.' (CA, carer for spouse)

> *‘A carer, what does it mean to me? A carer for a family member, especially a husband or the wife.’* (BR, carer for spouse)

Others derived the feeling of pride in being able to provide a high standard of care either themselves or by quality checking care provided to the family member by staff in a nursing home (see for example Davis and Nolan (2006):

> *‘When I went on holiday, she’d [the befriender] organised that [visits] so that he had a visit every day, cos I’d never left him before and that’s horrendous in itself, leaving him. You know, just because no one looks after him like I look after him.’* (BR, carer for spouse)

> *‘I think will in the end, I don’t think, it’s not a place where she [mother] will be left to sit. They [care home] have, this again is something that was important when I was looking at these homes is what activities they have. And this home seems to offer quite a few facilities. I think it’s important that someone with dementia’s stimulated, they are not left to sit.’* (PD, carer for parent)

Although not explicitly described as a coping strategy by carers, recognising and maintaining the personhood of the family member with dementia seemed to play a key part in enabling family carers to continue in the caring role and preserving their resilience (Bartlett and O’Connor, 2007). For example, for BR who visited her husband with advanced dementia in a care home, receiving what she perceived as expressions of emotional reciprocity from him, helped her to maintain an enduring closeness in their relationship and to continue with her visits:

> *And plus the fact that I’m there for him [husband]. I don’t know whether [husband] knows me or doesn’t know me but a few times when I’ve gone in and spoke to him he’s given me a lovely smile. You know, I’ll hold his hand and he’ll hold me and he will squeeze me [sic] hand. So to me I’m thinking he does, I’d like to think that he’s still got something that he knows who I am. So you’re there to make sure that they’re getting looked after the best possible way they can be.’* (BR, carer for spouse)

Some carers relied on their spirituality and faith for emotional and mental support, as the below exchange demonstrates:

> *'LO: So do you think if the time comes for you to use gadgets for yourself, would you be using them?*
>
> *CA: For him?*
>
> *LO: No, for yourself*
>
> *CA: God is my gadget! I'll pray god to be normal, because nobody, he can't look after me, so I just want to pray for to be well and healthy, that's all. It's not about the money, it's just to be well.'* (CA, carer for spouse)

Furthermore, as evident for the above excerpt, staying physically well was highlighted as an important aspect of being a carer:

> *'Well, while my mum is still alive I need to keep healthy, and that was the main object of involving myself in the trial [fitness monitor trial] to see how healthy I am. I did have an issue with blood pressure, but then I was told because of age sometimes the blood pressure does go up. But I try to take care of that by diet and exercise.'* (LN, care for parent)

Maintaining physical health was perceived by carers as key to being able to continue to provide care to the person with dementia. The interviews have shown that carers' conceptualisation of the necessity to maintain their physical wellness was framed by the perceived 'deficit of reciprocity', that is, the expectation that the person cared for would not be able to reciprocate and provide care should the carer become unwell.

Carers' perspectives on care were framed within familial responsibility, sense of duty, described through challenges faced daily alongside the lack of support from statutory services, poor quality of care provision from private agencies, pressures on mental health and physical wellbeing and anxieties about becoming unwell. At the same time, positive aspects were reciprocity, recognising personhood, 'curiosity', and maintaining one's resilience by endeavouring to keep physically and mentally well. The next section will examine carers' views describing rewarding experiences of looking after a family member with dementia.

5.4. Autonomy and personal independence in the context of living with dementia

In interviews with people living with early stages of dementia, ideas about personal responsibility for their own health and wellbeing and expectations relating to care provided by unpaid family carers were often discussed within the context of personal autonomy. This theme was often implicit within the conversations. By grouping the respondents' views on living independently in place into thematic segments it is possible to begin to understand how personal autonomy and (in)dependence are conceptualised by older people living with early stages of dementia.

Some aspects of autonomy and freedom, such as the importance of maintaining personal identity to the concept of dignity, discussed by the respondents within this study echoed findings of previous research carried out with older people and carers of people living with dementia (Woolhead et al, 2004; Sampson and Clark, 2015). Making decisions about with whom to associate, engaging in satisfying leisure activities and hobbies such as gardening, independently maintaining daily routines and taking care of pets were listed alongside other ordinary activities thought to enhance one's autonomy. Other examples from everyday lives given by the respondents with dementia, such as an unexplained and unexpected withdrawal of the driving license or being excluded from making decisions about whether or not to have assistive technology items in one's dwelling evidenced occasions when opportunities for autonomy were jeopardised or negated (Woolhead et al, 2004).

Themes of self-managing and retaining independence and wellbeing through daily activities were salient throughout the interviews. Self-reliance was regarded by some respondents as a source of pride and personal self-sufficiency. For instance, for one of the interviewees, JK - who is in his 90s and lives alone in his house - the definition of 'independence' included being able to manage on one's own without external help:

> *‘JK: You’ve got to try to organise yourself to get some results, whereas if you didn’t bother and one thing and another, well you wouldn’t get anywhere. And I think independence is very, I think a – it’s personal what is required and you can’t always rely on other things and other people and all that, you’ve got to do something for yourself.’* (JK, person with dementia)

The idea of personal independence was also linked by JK to overcoming mental and physical obstacles presented by living alone and coping with a memory impairment. Being able to exercise a degree of control over his life gave JK a sense of achievement and reinforced his desire to continue to live in his own place:

> *JK: Well to be independent, it’s very strengthening mentally and physically because you encounter all sorts of things and although it passes through the mind ‘Oh shall I go and see so and so about that? No, get it done!’ And you think for yourself and you’ve got to get on with it. That’s my opinion about it anyway.* (JK, person with dementia)

JK attributed his reluctance to seek external help and to maintain an independent way of living to his personal strengths of character developed as a result of his upbringing:

> *‘JK: But a lot of it is from A to Z is how you’ve been brought up.’* (JK, person with dementia)

At the same time, he regarded those accessing publicly provided services as lacking in strength and asking for something that they do not necessarily need or deserve:

> *‘JK: I think if there’s more independent people in this country, we’ll be a better country. I do indeed. There’s too many people who could be independent leaning on the system and it’s not required.’* (JK, person with dementia)

It can be said that JK’s views on autonomy, independence and seeking help are an integral part of his personal identity linked to his understanding of dignity and self-esteem. It is clear that JK derives his self-respect from his sense of achievement stemming from coping with everyday tasks in the context of living alone and adjusting to impaired cognitive functions caused by dementia.

‘Looking after oneself’ without relying on family carers or paid workers was regarded by JK as one of the markers of personal autonomy and independence. Daily routines that may be considered mundane and unexciting by some, and whose completion may be taken for granted by the majority of individuals, were discussed with a sense of pride by JK:

> *‘But no, I read a lot and I keep the place pretty shipshape, you know, and do the cleaning and that, and do the cooking, and look after myself as best as I can.’* (JK, person with dementia)

The theme of being able to cook for oneself independently was evident in interviews with other respondents. For instance, MO a woman aged 68, living alone in her own flat, who has been diagnosed with vascular dementia

> *‘MO: I try to go out every day just to keep mobile, really. And I do me own work, not as well as I should be, probably, but I do me own meals, cook me own meals.’* (MO, person with dementia)

Doing household chores, cooking, managing own finances and, most importantly, going out were among the markers of personal independence discussed by MO. Acutely aware of the increasing impact of memory loss on her everyday activities, MO used reminders in the form if extensive lists and post-it notes with instructions to self in order to continue performing everyday tasks:

> ‘*LO: Do the notes help?*
>
> *MO: They do, yes, because I always sit at the table to have me meals so I see what's written down. I sit on that chair there with me back to the door. I don't know why I sit there but I do and I read my notes. And I try to put them in date order. And I also put them there on the calendar, so you know I don't just have it in one place, just to make sure. Otherwise I would forget. Yes. I just see if there's anything on there, to see what I've got to be doing. How long I've realised that I should be doing that I don't know, I don’t know what'll happen then. It's quite frightening really, if you think about it, if you dwell on it. I try not to dwell on it.’* (MO, person with dementia)

Using notes and lists as reminders was a well thought-out strategy put in place by MO to enable herself to continue living without seeking help from either family members or social services. While admitting to herself that her memory was deteriorating, to outsiders MO presented an image of herself as a competent and confident individual who copes well living alone. This was evidenced by her having hidden the reminder notes prior to the research interview, as the exchange below demonstrates:

> ‘*MO: I write most things down.*
>
> *LO: Do you write notes for yourself?*
>
> *MO: I do but I've hidden them all today [laughs]. I have them on the table there but I just thought I've got to tidy this up.’* (MO, person with dementia)

Reminder strategies and tools therefore can be viewed by people living with dementia as both enhancing and impeding independence, the former being achieved through daily list making and completion of household chores written down, and the latter occurring when family members or visitors notice the reminders and become aware of the extent of memory impairment and its impact on the person’s daily life.

Continuing to manage own finances was regarded as another activity that enhances personal independence in the context of living well with dementia. MO, for instance, talked with pride about being able to manage her own money without asking for help, and at the same time shared her concerns and even ‘dread’ about the impact of memory deterioration on her ability to budget, and a loss of independence as a result:

> *‘MO: I mean I have managed quite well meself [sic], you know, and I handle all me own money and I dread the day when I've got to part with me money to somebody else. Yes, I dread the day of that. In fact I'm dreading getting worse.*
>
> *LO: And letting someone else manage your money, is it a sign for you of losing independence?*
>
> *MO: Completely, completely.’* (MO, person with dementia)

This theme is echoed in an interview with another respondent – JB, aged 76, who, although not living alone but with his wife who is his primary carer, has always taken the responsibility for managing family finances, including savings and investments. JB has continued in this role even though his memory deterioration was obvious to him and his wife, and was the cause of him losing a few bank cards when he tried to withdraw cash from cash points. On the day of the interview in his house, JB received a replacement card in the post, which he opened in front of me and even tried to hand it over to me, a stranger, so that I could 'have a look'. Nevertheless, managing finances was linked by JB directly to personal independence, as the quote below demonstrates:

> '*LO: So when we speak about being independent, what does it mean to you?*
>
> *JB: Well we don't have to get involved with anybody else if we are deciding to do something, we want it done or we'd like it and then I just check out if we've got enough in the building societies and banks where we've got money invested.'* (JB, person with dementia)

Despite being challenged by his memory problems, both JB and his wife seemed to be content with him continuing to manage the family finances thus maintaining what some researchers have described as 'traditional gender roles' in the household (Hulko, 2009: 140).

The connection between personal financial security and self-sufficiency was made by another interviewee – JK, some of whose quotes were discussed above. JK's construction of personal independence as a trait of the individual's character, developed by his upbringing, included financial acuity and discipline. He spoke with pride about having the strength of character which he believed enabled him to live within his income, as the quote below demonstrates:

> *'LO: So we were talking about being independent and living in your own house.*
>
> *JK: Oh I've been independent, both financially and physically, I'm brought up that way. What you can't afford, you don't get, that was the attitude of my father. I've been in the service where you're forced to be independent. I've just slotted in with it.'* (JK, person with dementia)

Being financially independent, according to JK, had a positive impact on his mental wellbeing and life satisfaction. In the interview JK stated a number of times that he felt he led a ‘good life’ and managed well living alone:

> *‘JK: No I can’t think of anything else that I would want to make life better. I mean I’m living off my state pension, I’m living off my pension that Civil Service and bits of money that I put here, there and everywhere, or we did - [wife] and I because I, it came my way then to look after her. No, I’m quite happy with what I’ve got.’* (JK, person with dementia)

As the above quotes demonstrate, having financial capacity was regarded by the interviewees as essential for functioning independently. Continuing to manage family or their own finances was a source of a positive outlook on life, while the realisation that this ability was gradually diminishing because of the cognitive impairments associated with dementia produced feelings of dread and hopelessness in the respondents.

Another source of frustration and negative emotions was the withdrawal of the driving license which was seen as unjust, arbitrary and disabling by the respondents living with dementia. The findings from the interviews with people living with dementia have supported findings of earlier research (see for example Sanford et al, 2019) – that the driving assessment resulting in a revoked driving license was a source of the feelings of loss of independence akin to grief and a disruption of identity to people who relied on driving for a long period of time. For instance, for JK the withdrawal of his licence was unexpected and caused him much frustration, as he felt that he was a good driver and had not broken any rules:

> *‘JK: Oh I used to do that [to travel], correct, correct. I used to do that when I had my driving license. And I don’t know why they stopped my driving license, I hadn’t done anything wrong. But that’s another matter.’* (JK, person with dementia)

5.5. Befriending and the limits of care

In the geographical literature, friendship has been theorised as an important source of informal care and support in such major life events as illness or incapacity (Bowlby, 2011). Its main components are choice, reciprocity and fluidity, with boundaries between individuals changing over time (Andrews et al., 2003). Friendships and social interactions with non-family members are considered to be beneficial for preventing loneliness and social isolation in older people (Antonucci et al, 2001; Fuller-Iglesias et al, 2008). Fostering friendships between people living with dementia and volunteer befrienders or paid companions was the main objective of the two schemes examined by this case study. For instance, a member of staff at the Companions scheme located in North Wales described the interaction between clients with dementia and companions as follows:

> *'…they [people with dementia referred into the service] can make acknowledgement with the companions and they can build that relationships with the companion, and with the actual persons that they're going out with to actually bond, form a friendship.'* (JR, Service Development Worker)

Liverpool-based befriending scheme where services are delivered by volunteers also had 'friendships' between volunteers and people with dementia at the core of its mission, as described by the Project Worker:

> *'I work with befrienders, so their role … that we've kind of developed now, their main priority's to support, empower, enable the person and build that relationship.'* (GA, Project Worker)

While there seemed to be a consensus among members of staff with scheme management and volunteer coordinating responsibilities that friendship is an essential element of a befriending relationship, in-depth interviews revealed more nuanced understandings of both friendship and befriending. Firstly, friendship was described by interviewees as a relationship that is 'natural' and genuine corroborating theorisations of friendship as 'a relationship of choice' (Andrews et al., 2013: 350) or a 'voluntary relationship' (Bowlby, 2011: 607) within the existing geographical and social science literature on friendship. For example, below statements made by members of staff at the befriending scheme offer a clear illustration of this point:

> *'…so it's just about … being a friend to someone, and I don't think you can write down how to be a friend. I think it's just [one of] the most authentic things that happen really naturally…'* (GA, Project Worker).

> '…a friendship has to be a natural thing almost. But I do think that befriending quite often does lead to friendship… I do think that befriending, and we've seen it happen so many times, does then lead to friendship.' (UJ, Head of Services).

Secondly, as the second quote demonstrates, some of the staff members felt that a befriending relationship is comparable to a friendship, or that it can transform into a friendship over the course of time, a view also shared by some of the volunteer befrienders:

> *'… I mean, it's almost in the essence of the word befriending, you know, you go out of your way to become somebody's friend.'* (BS, Volunteer Befriender)

However, further discussions with befrienders and staff relating to processes and procedures existing within the services revealed more complex views of befriending marking a departure from the respondents' initial statements which equated befriending with friendship. Firstly, unlike friendship, the befriending relationships facilitated by the scheme did not have entirely voluntary beginnings, as the below quote from a senior staff member demonstrates:

> *'It's hard because you are forcing the friendship on two people really, that's essentially what you're doing. And sometimes it works and sometimes it doesn't.'* (UJ, Head of Services)

All befriending relationships, supported by both schemes, were initiated either by family members of the persons living with dementia or health and social care professionals who came into contact with the individuals and identified them as being at risk of social isolation, thus rendering the relationship less spontaneous or 'natural' and more contrived at the outset. Furthermore, I have found that formal codes and procedures that the services and volunteers had to follow introduced a greater degree of tension into the relationship between the befriendee and the befriender. As previous literature on friendships has suggested (Andrews et al, 2003; Phillips and Evans, 2018), and what this study has revealed from the befriending examples considered here, friendships are based on more natural and organic unwritten rules and are strengthened by shared experiences, rather than something more formal, such as a contract. As a result, what is evident is that the service protocol employed by the scheme, clearly delineated professional boundaries of the befriending role reducing its remit to companionship, listening to the person and friendly conversations, thus limiting opportunities for less scripted interactions underpinned by mutual curiosity. The quote below, from a befriender, serves as an illustration of this tension:

> *'… I don't know if it's a friendship, well, it probably is a friendship but more just keeping, you know, keeping somebody company. And I wouldn't say it's like a caring responsibility because it's very limited what you can do.'* (CDS, Volunteer Befriender)

The interviews with the befrienders have demonstrated that at the start of their relationship with the befriendee most of them found it difficult to describe the relationship as a friendship. Neither did they describe it as support work or care work. Thus, a befriending relationship occupies an 'in-between' position, a newly emerging relationship with the potential to transform into a friendship with time as well as including elements of care provision, such as feeding, clothing and personal care.

Despite the formal contracts in place, many befrienders transgressed the boundaries of the role set by the service and reported undertaking extra activities, including doing minor household chores and providing personal care, as the below excerpt from an interview with a befriender evidences:

> *'… she [person with dementia] was kind of asleep and she had food all down her, like all down. She dropped her food to her bed and it was all spilled everywhere, she had it all over her face, everywhere basically, in her hair and everything. … I just mopped, like cleaned all her, yeah I think, I might have cleaned her face first actually, and I rang them [the scheme]. But [scheme] worker was like 'Don't clean the sick, it's not your duty,' and I was like 'Well I've already done it because I'm not going to leave her sitting with sick all over her face. There's no dignity in that, I'm just helping her as a person'.* (SG, Volunteer Befriender)

Other examples of befrienders ‘doing extra’ related to transgressions of temporal limitations applied by the service. The befrienders were advised to spend no more than four hours per visit with their befriendees, yet some reported spending a significantly longer time on visits, particularly when they went on day trips or undertook other activities, such as attending a cricket match:

> *‘LO: Do you find it difficult to stick to these [scheme-defined] boundaries?*
>
> *DPL: Sometimes yes, because especially, you know I wanted to go to cricket with M and it took you out of [the scheme’s working] hours when you could report in. Well I’d be quite happy to do that but I don’t think, in fact I did once go to a game of cricket where we went out of, we went out of hours.*’ (DPL, Volunteer Befriender).

Befriender recruitment and matching processes followed by the scheme were lengthy and rigid. Members of staff who carried out needs assessments with people with dementia and their carers interviewed potential volunteer befrienders and selected suitable candidates, who were then required to undergo a disclosure and barring service check (DBS). Following a satisfactory outcome of the DBS check, volunteer befrienders were required to complete a form in which they outlined their interests, hobbies and aspirations. This information was then compared by staff to information about interests and hobbies collected from the person living with dementia or their carer in order to identify commonalities.

Friendship and befriending are described as something ‘authentic’ and ‘natural’ taking place between individuals interacting with one another in an unpaid capacity. As the quotes below from befrienders illustrate, some of them shared these understandings of befriending and friendship:

> *‘I really think it’s important because if you start saying like ‘Oh yeah I’ll come next week’, and then you don’t turn up then they’re like trying to rely on someone or looking forward to something and you’re letting them down, then that’s just, that’s not how you build a normal friendship. So I don’t think you would build a befriending relationship on that level of letting people down and being inconsistent. I feel like*

> *that's quite an important factor for friendship, being reliable.'* (LST, Volunteer Befriender)

It is evident from the above quotes that the words 'befriending' and 'friendship' are at times used interchangeably by members of staff and befrienders reflecting their seemingly intertwining nature. However, further exploration of befrienders' views on the nature of the befriender – befriendee relationship, the befriending role itself, and the interrelationship between befriending and friendship has revealed conflicting feelings experienced by befrienders in relation to the remit and professional boundaries of the voluntary role. Considering these views through the prism of geographical understandings of friendship is beneficial for addressing some of the main areas of this study, such as the interplay between intergenerational and voluntary aspects of befriending, the role of shared material spaces and memories in the creation of friendship bonds, and the impact of virtual spaces created through technologies of communication on practices of care that exist between family carers and people with dementia.

'Appropriate matching of client to befriender was seen as an important first step in relationship building. In particular, good matching appeared to be a prerequisite for the development of an enduring relationship (Andrews et al, 2003: 356 – 357)

Although the geographical aspect of friendship, that is, its fundamental role in connecting people across distance and at proximity is under theorised in human geography, scholars who have focused on friendship have defined it as relationship between two or more people characterised by its voluntary nature - that is a relationship which is entered in and dissolved voluntarily (Bowlby, 2011; Bunnell et al, 2012). Other key factors affecting the formation and sustainability of friendship bonds include shared material spaces, such as workplaces, schools and pubs, as well as virtual spaces created by communication technologies including social networking platforms and web applications (Bunnell et al, 2012).

> *'How we match people is by similar likes, dislikes, interest, hobbies. You know, we find common ground between the two people and then we match them. Sometimes they might go out and might not like one another, and that's fine because not everybody likes everybody. And if you want someone to support you and be in your*

> *home you've got to feel comfortable and confident, you know. We'll match you with somebody else and that's fine. So yeah, we don't do it geographically or gender. What we do it on is, you know, on your personality and your likes and dislikes.'* (GA, Project Worker).

The collection and meticulous recording of personal information was perceived by members of staff as essential for the creation of a successful befriending relationship:

> *'So I feel like we just try and celebrate everybody's differences and, you know, we have a document to capture people's likes, dislikes, thoughts, feelings and experiences, and it's called the 'All about me' document. So we use different things like that to try and capture everything that we can, and that's what we use to match… We also, when we're doing training, we ask for people to fill in, we do different, we always use different ways of getting information but we'll have like for example the 'shield of life' where we'll have hopes about becoming a befriender, fears about becoming a befriender and then we'll ask a bit about themselves. It's shaped like a shield but there's different ways of extracting different information, and this is key into finding out about people's, you know, what's important to them in life.'* (GA, Project Worker).

If shared interests were found, an initial meeting between the befriender and the befriendee was arranged, attended by the scheme's coordinator who facilitated and supervised the interaction, and, if appropriate, a family carer:

> *'But we always have an initial matching meeting first as well, and that's when the befriender and befriendee will, you know, see if they like each other. Hopefully we've picked the commonalities between them and then, hopefully, they can draw on that in that first meeting. And sometimes, well the majority of the time, it's fantastic and they really like each other.'* (GA, Project Worker)

Although members of staff felt that the 'matching by interests' approach to initiating a positive befriending relationship was largely successful, befrienders reported a lack of understanding of how they were matched, as well as a combination of positive and negative results of the matching process:

> *‘I honestly don’t know [how matching was done] because I didn’t think it was as close a match as all that in a sense, so I don’t, I don’t know how it was done really. And certainly the other man [service user], there was very little between me and him in common other than I suppose football, so I’m not sure how that was done really. We’ve always got on well with him. We don’t talk about sport or cricket, or anything like that in any depth really, but we’ve always got on well with him, there was never awkward silence or anything like that at all, but I’m not sure how they matched us.’* (DPL, Volunteer Befriender)

> *‘Well, you know I don't know [how matching was done]. All I know is that before I started doing it I went out shadowing somebody who is, I think she is actually a social work student and she befriended a few people. And she took me out on a few visits with her. And then, I mean we chatted and you know, obviously I interacted with the different people. And then I just got notified that I was being allocated to this particular service user. And it's worked very well, I mean we had and have a lot in common, you know, our interests in art, sense of humour and our music tastes and everything else. So it did work really really well. So whoever decided to match us made a good job of it, but I don't know how, I don't really know how it was done.’* (BS, Volunteer Befriender)

According to Andrews et al (2013: 351), ‘all friendship relationships have fluid boundaries, in that over time they can become deeper and more meaningful, or retract and dissolve.’ This fluidity of boundaries was observed in the relationships between befrienders and people with dementia, with some befrienders describing the relationship as ‘just company’ and others reporting strong bonds that developed over time. From the interviews with befrienders and befriendees I observed that stronger friendship bonds developed in those relationships where both parties travelled together to new ‘unknown’ or familiar places. That those who reported stronger and longer-lasting friendships also engaged in shared activities, such as attending community clubs, sports stadia, museums and pubs.

5.6. Concluding Remarks

In this chapter, I have explored some of the key ways the responsibility for care is understood by family carers, professionals and service providers. The quotes presented in this chapter demonstrate significant differences in the way responsibility for care is constructed: while the professionals and service providers present the discourse of self-reliance, self-management and individual responsibility for care, discussed in chapter Two (see Lavalette and Ferguson, 2013; Lawson, 2007), the experiences of carers of people with dementia demonstrate that they already rely largely on own resources with little support from statutory services or private care providers. Interviews with the carers have shown that this has negative implications for their mental and physical health, including high levels of stress, feelings guilt and social isolation. Exploring the views of people with dementia on personal autonomy and independence, I have found that themes of self-reliance and having control over one's finances and the daily life were salient throughout these interviews. These aspects were important to people with dementia not because they were concerned about achieving reductions in spending to publicly funded services, as was the case for the professionals, but because they were inherent parts of their personal identity.

In this chapter I have also explored the transformations that befriending relationships underwent though time, with some developing into friendships engendered and enhanced by participation in shared activities and visits to new, previously unexplored places.

Chapter Six will extend the discussions presented above by examining respondents' views on and experiences of care in the community.

Chapter Six: Spaces and places of care

6.1. Introduction

In this chapter, I examine the lived experiences of people with dementia and family carers of providing and receiving care in the community. In doing so, I seek to contribute to the literature on family carers' negotiation of community support or lack of thereof, and make visible the challenges they encounter. Section 6.2. presents the analysis of the concepts of care and familial responsibility for care from the point of view of carers themselves. In section 6.3. I explore how distance and proximity affect the practices of care and impact of relationships within extended families looking after relatives with dementia. Sections 6.4. and 6.5. examine the experiences of people with dementia of growing old in place and at home, and discusses strategies they employ to maintain their personal identity, preserve autonomy and continue to enjoy well established social connections.

6.2. Care in the community

An examination of narratives from the interviews with family carers has revealed different experiences of being a carer for a person with dementia in the community. Talking about their local communities and relationships between neighbours, some carers offered a deficit-based account where the community was considered to be under threat of vanishing, while others described a relationship characterised by solidarity and mutual support. PD, a male carer in his mid-fifties who looked after his mother with later stages of dementia gave a pessimistic account of his local community where he felt he could not rely on help and support of his neighbours. PD's quote below also highlights the discrepancy between professionals' expectations that the community and neighbours should provide support to carers looking after their family members and the reality in some of the communities, where such support is non-existent:

> *'LO: What about the support that you get, any friends, family members?*

> *PD: We didn't, right. We don't and it's general now, you don't have neighbours. Where I live is now basically student accommodation. There is a couple on my right, they're out at work and the woman on the left keeps herself to herself, so when you ring social services up for help, the first thing they say 'What about your neighbours?' [laughs sarcastically]. And as I say I think it goes for most people. We don't have neighbours anymore, people keep themselves to themselves.'* (PD, carer for a parent)

According to a study by Bamford and Bruce (2000) into the outcomes of community care for people with dementia and carers, having a sense of being socially integrated into one's community was one of the desired outcomes for both groups. Carers particularly valued neighbours' support with monitoring the movements of the person with dementia outside the home. Similarly, this study has found that the carers valued locally available help and support from neighbours and local residents in their communities, and, as the case of PD has evidenced, felt disappointed and dissatisfied when these were not available to them.

Further interviews with carers showed that PD's experience was not shared by all participants. Another carer, AF, provided an account of a connected community characterised by neighbourly support. Awareness of one another's needs shared by the residents and their willingness to help, according to AF, contributed positively to people's wellbeing. Indeed, other studies (see for example McConaghy and Caltabiano, 2005) have found that informal support in the community protected carers' psychological wellbeing and contributed to higher satisfaction with life.

> *' […] community is having good neighbours so knowing that if the neighbour hasn't seen you or milk's still on the step that somebody will give you knock and just say 'Are you OK?', contact the family if you haven't been seen, so it's having that neighbourliness that also enables to stay well.'* (AF, carer for parent)

According to AF, she felt privileged and 'lucky' to live in a neighbourhood where people knew about one another's circumstances and care needs and arrangements, and were willing to attend to the person receiving care if they had any concerns about the individual's wellbeing:

> *'I'd say certainly my road, we're quite lucky, there's three single women in the road of over pension age and one being me mum, and we all do look out, like we know the lady over the road has carers so we know when the carers have been, she's OK. My mum and the other lady who both live alone, you know, if P's milk's still out then somebody will knock.'* (AF, carer for parent)

In contrast to PD who felt that he could not draw on his neighbours' support with care for his mother and believed that this was a common experience, AF thought that strong communities could be found in less affluent parts of the city. Research by Keady et al (2012) into the provision of care to people with dementia by members of closely-knit communities has found that friends, neighbours and acquaintances of those with dementia are instrumental in provision of supportive services. Furthermore, a study by Wiles et al (2012) into resilient ageing in economically deprived communities found that the socio-economic status of the residents did not preclude older people from ageing successfully. The lives of older residents in the study were characterised by long-established micro-communities and networks of support and reciprocity among neighbours which were a source of resilience in older people's lives (Wiles et al, 2012). Views from some of the respondents in this study have echoed the findings of the study by Wiles et al (2012), as, for example, AF's quote below demonstrates:

> *'So yeah, I think it depends, I think the more, what's the word, the more deprived areas, I live in [area in Liverpool], it's one of the biggest deprivation areas of Liverpool, we are very community-minded. I think if you go to the more affluent areas where people aren't there all day every day, I think there is a bit more isolation, that's what I think.'* (AF, carer for parent)

Among the family carers who took part in interviews, AF was unique in expressing positive views on community support. For others negotiating support from the wider community, friends or even family members was a source of tensions and conflict, often resulting in little change to care arrangements where the same primary carer would shoulder nearly all responsibility for care (see for example Milligan, 2003). Consequently, social isolation was one of the most salient themes emerging from the interviews with carers, as illustrated by the quote below:

> *‘You become very lonely. It’s a very very lonely disease because people don’t come near you, friends, you know, they tend to run away from you more so than come and knock and see ‘Are you alright? Do you want a cup of tea? Is there shopping you need? Can we do anything?’ You’re on your own, you’re sitting on your own.’* (BR, carer for spouse)

Social isolation in carers of people living with dementia has been well documented by previous research (Bond et al, 2005; Beeson et al, 2009). Beeson et al (2009) have found that female carers in particular experience higher feelings of loneliness, relational deficit and depression than male carers. Thus, BR’s experience of being a carer characterised by social isolation and poor mental health unfortunately corresponds with experiences of other female carers described in international studies (see for example Sörensen et al, 2006).

In another interview a respondent who shares caring responsibilities for her partner’s parent with her partner said that she believed ‘care in the community’ in reality meant that responsibility for care largely fell to one person, often a single female relative, or a couple without children:

> *I think unfortunately it [care in the community] does often mean that there’s one person that takes the responsibility for that… We’ve got caring responsibilities for my partner’s mum and we are the only couple not to have children. And then it’s seen as ‘Well you’ve not got children so therefore you’ve got time’. And so there’s always a natural assumption that you’re single, you’re female, you haven’t got children, whatever it is, but people assume that you’re OK to do it then.’* (SC, carer for a parent-in-law and volunteer befriender)

Having recounted the difficulties, frustration and confusion that she and her partner faced while negotiating support from community-based services, SC pointed out that often additional pressure on carers came from within the extended family itself, with members in effect informally selecting and appointing a primary carer:

> *‘But I do think that more than ever there’s a responsibility falling on family members to provide that care. And family dynamics often kind of dictate as to who that’s*

> *going to be and who it's not going to be.'* (SC, carer for a parent-in-law and volunteer befriender)

With limited tangible involvement in care from family or friends the primary carer would take responsibility for an extensive range of tasks – from navigating the system of social care, to meal preparation, organising GP and hospital appointments and accompanying the family member with dementia, physical and personal care and socio-emotional support. Among these aspects of care, accessing publicly funded support services for the person with dementia as well as for oneself was reported by carers to be the least straight-forward task. For example, WL who cares for her mother living with later stages of Alzheimer's disease explained:

> *'Social services are a different breed altogether. Social services are hard work. Social services, they are supposed to be there to help but it always feels like there is a barrier and you've got to get over to just get through with things with them, so that's another story altogether. I dread it when I get a voice message from them saying, because just I know it's that whole cycle of ringing and then they ring back, and we never get to speak for like a week later, oh no. I know they must have a high demand but there needs to be a re-evaluation of the whole system.'* (WL, carer for parent)

Although WL's professional occupation in the National Health Service gave her an insight into the workings of the health and social care systems, she nevertheless struggled to navigate them and to negotiate their complexities successfully in order to access adequate support for her mother. WL's experiences were not unique, the majority of carers interviewed for the study reported being confused by often opaque and haphazard ways in which the system of social care operates. Confusion, social isolation and stress caused by the pressures arising from battling the system led some carers to believe that other family members, particularly those who were geographically distant, could and should offer more support and take on a more active caring role.

6.3. Caring at distance

The subject of distance and proximity between people living with dementia and their family members emerged as a common theme amongst carers, which can be further divided into two sub-themes. Firstly, as SC explained in the quote below, the decision about which family member should take on the role of the primary carer is often determined by the proximity of this family member to the person with dementia, rather than any considerations based on the person's willingness or suitability for the caring role. The decision is often made by other family members living at a distance, further illustrating SC's point about families 'appointing' the primary carer:

> *'So there is a lot of geographical changes because of the way society is kind of progressing and therefore anyone that is within the close geographical range often it's not even about appropriateness, it's just the fact that they're the closest person so it will fall to them.'* (SC, carer for a parent-in-law and volunteer befriender)

Secondly, commenting further on the rising tensions between family members within her partner's family, SC linked the cuts to publicly funded care services to the pressures faced by families who shoulder the bulk of responsibility for all aspects of care:

> *'I think the cuts and just the kind of the way that our social care system is going, there is an overreliance on family to provide that support and care for family members and not enough information and support for carers.'* (SC, carer for a parent-in-law and volunteer befriender)

Discussions relating to the social and structural constraints on family members' abilities to provide care, such as familial demands and gaps in state-funded social care service provision, were prominent in the carers' narratives. Some of the geographically proximate carers held highly negative views of the support offered by those who lived at distance. For example, when asked about the involvement of his geographically distant siblings in the care for their mother living with advanced dementia, PD explained that he didn't think that 'distance should be a problem to anybody'. He gave an account of an emergency situation when his brother who lives in another city was able and willing to come as quickly as he could:

> *‘Brother lives in N and he will come down at the drop of a hat. Well, one morning I rang him, once I rang him at quarter past twelve cos I had to call an ambulance and he was with me at quarter past one.’* (PD, carer for parent).

At the same time his sister’s perceived unwillingness to offer more support was a source of anger and frustration to PD, as the exchange below demonstrates:

> LO: *‘What about other family members?’*
>
> PD: *‘Right oh yes, I’ve got a sister who is not a lot of help. She lives out in S. I know public transport isn’t reliable…, but no, distance shouldn’t be a barrier to anybody.’* (PD, carer for parent)

Echoing SC’s views of tensions within ‘family dynamics’ discussed above, PD felt that the source of his sister’s lack of engagement with care for their mother could be traced to a possible breakdown of the relationship in the past:

> *‘My brother and meself [sic] can’t work out but something’s gone on in the past that’s made her [the sister] the way she is.’* (PD, carer for parent)

These accounts from family carers pose a challenge to views expressed by some social care services commissioners and providers, discussed in chapter Five, who believe that families, neighbours and communities can be relied on to take a greater responsibility for the care of people living with dementia. Professional stakeholders who took part in the study often identified families and communities as a resource that can be called upon in order to ‘relieve the pressure’ on an ‘over-tasked and reducing [health and social care] workforce’ (TS, CCG). To sustain ongoing reductions to social care budgets some of the stakeholders such as TS in this instance, suggested ‘bringing a wider community to the care package’. However, the analysis of the carers’ narratives has revealed that not only were there significant variations in carers’ views of and access to ‘supportive communities’, but also that support from families was not universally available and largely contingent on ‘family dynamics’. All but one geographically proximate carer taking part in the study shouldered the bulk of care responsibility for the person with dementia alone, with occasional help from other family members offered through visits and phone calls.

The geographical proximity and distance of the primary carer to the person receiving care was another common theme in the narratives of family carers as well as people living with dementia. While some carers, such as PD, maintained that it was not the distance that had an impact on the quality of the relationship between the carer and the person with dementia but their shared family experiences and history; others found that distance and travel it necessitated brought additional challenges to their caring role. For example, BR who regularly visited her husband in a nursing home described the long journeys she had to make and their negative impact on her health and financial wellbeing:

> *'[I visit my husband] more or less every day. Yeah. Normally Tuesdays, but there has been a few Tuesdays when I've gone when he's not been well and I had a phone call I'll go straight up regardless. And Sunday. And Sunday is normally because of the bus service. If me [sic] daughter's not around to take me then I don't go because I get 3 buses to go and see D. If I go another way I can get 2 but it takes me longer. So Sunday service, you know, and I thought it's going to take me twice as long just to get there. If it's really bad, now and again I'll say 'Oh I'll just have to go, I'll have to get a taxi'. Me blood's been really low in iron, so me bloods are down, I'm really struggling with that because I'm constantly tired… And there's that times where I think 'I just can't face the buses, I can't', and I've jumped a taxi back. But you don't get paid for that, you've got to budget.'* (BR, carer for spouse).

BR cared for her husband D, who was diagnosed with an early onset dementia at the age of 55, for a number of years until she could no longer cope with his increasing care needs, significant changes in his behaviour, and the physical aspect of care. BR herself experienced a decline in her health and eventually D's place of care transitioned from the family home to a specialist nursing home. Consistent with other studies on family carers' involvement in care-giving within residential and nursing homes (Kellett, 1999; Milligan, 2006), BR's experiences of the transition were marked by stress, depression, feelings of worry and guilt. The transition also triggered new concerns which related to the organisation of the visits to the nursing home and the quality of care provided by the staff:

> *'I'm there to make sure that D's getting the best possible care, that he's not being left or if he needs things… I've had to make sure they're [staff at the care home]*

> *getting the dentist in because his teeth are going terrible and I've had to go on at them. So we've got a dentist coming in. So I cannot just let him go cos he's mine and I do love him so I'm basically standing over, watching that he's getting what he should be getting as a carer. So you're there to make sure that they're getting looked after the best possible way they can be.'* (BR, carer for spouse)

As the above narrative indicates, D's transition to an institutional setting did not mean the end of caring for BR, as she continued to visit D daily and undertook a range of tasks within the home. In addition to monitoring the quality of care, BR engaged in what Milligan (2006) has termed 'the emotional work of caring' (2006: 325) – giving companionship and affection to her husband. BR talked warmly about her time with D:

> *'And plus the fact that I'm there for him. I don't know whether D knows me or doesn't know me, but a few times when I've gone in and spoke to him he's given me a lovely smile. You know, I'll hold his hand and he'll hold me and he will squeeze me hand. So to me I'm thinking he does, I'd like to think that he's still got something that he knows who I am.'* (BR, carer for spouse).

Family members' continued involvement in care for individuals with dementia after their admission to residential or, as in D's case, nursing care has been identified by health geographers as a contributing factor to the blurring of the boundaries between formal and informal care giving (Twigg, 2000; Milligan, 2006). While the penetration of formal care into home space has been relatively well considered (Milligan, 2006), the performance of informal care by family members within more formalised and regulated spaces of institutions is still under-researched. A more thorough examination of this issue and its impact on the interrelationship between paid carers, unpaid family members, volunteers and care recipients within multiple settings and across a range of scales can contribute to a better understanding and responses to dementia care. Notably, experiences of family carers who provide the continuity of care to individuals with dementia following the transition of care, as BR has done for a number of years, poses a challenge to the discourse of family care deficit used by some commissioners, service providers and other professionals to endorse the current cuts to publicly funded social care provision (see chapter Five). While some commissioners who took part in this research insisted that it was a part of their role to ‘get people to do more things for themselves and their families’ in order to make the social care system more efficient, it is clear from BR’s example that many carers were already heavily involved in the provision of care to their family members with dementia not only within the home but also after the transition of the place of care to an institution.

In providing the continuity of care to D, his wife was supported by a volunteer befriender – BS who continued visiting D in the nursing home. BS visited regularly once or twice a week, including the times when BR was not able to visit. Although BS was not sure whether D still remembered her as his memory had deteriorated, she felt that her visits had a positive impact on his wellbeing as she was ‘a friendly face’ with whom D liked spending time:

> *‘I mean I still visit him, but we have a limited engagement now and I'm not sure he really remembers who I am, but I'm a friendly face.’* (BS, befriender)

In this example, it seems that even though the place of D’s care transitioned, his social support network, consisting of his spouse, his children and the volunteer befriender adapted to the change by moving away from supporting him at home to the institution. Thus, a part of the community on whose support both D and his spouse were reliant was preserved even though ageing in own home was no longer an option for D. This was only possible because of the strong bonds of friendship that had developed between the volunteer, the carer and the person with dementia over time, as well as the befriender’s continued goodwill. In other cases that this study examined support from befrienders ceased when the place of care transitioned from the home to residential care.

As noted earlier, some family carers, as in PD’s example discussed above, strongly believed that ‘distance should not be a barrier’ and felt that geographically distant family members did not shoulder their share of responsibility for the of the relative with dementia.

An examination of accounts offered by family members living remotely has revealed that some of them share the opinion of the geographically proximate carers that they could and should offer more support. Feelings of guilt and their negative implications for the carers’ mental health, discussed in Chapter Five, were also present in those who identified themselves as ‘distant’ carers. For some, like OL who supported his mother at distance to provide care for his father with advanced dementia, trying to balance the time with his family with the visits to his parents was a source of conflicting ‘weird’ emotions:

> *‘It [being a ‘remote’ carer] is really weird and I think it plays into sort of psychology, because you’ve got all these kind of really weird emotions, you know there is an emotional side to it as well.’* (OL, distant carer for parent).

Although OL travelled to see his parents most weekends, he nevertheless felt that he was not doing enough. He maintained regular contact with his mother through phone calls, and at the interview OL raised the possibility of communicating with his parents via Skype, which will be discussed in chapter Seven in connection with discussion of technologically supported care. Throughout his account, OL continued returning to the impact the distance had on his relationship with his parents as well as his own mental wellbeing:

> *‘Caring at a distance is hard, and probably, I suppose more people are going to get into this situation with parents in different parts of the country or different countries even. It is a really difficult one.’* (OL, distant carer for parent).

OL was concerned that he may be perceived as sounding ‘kind of cruel’ when he described one of the coping mechanisms that he used in order to deal with his emotional stress:

> *‘So it’s a kind of a balance but it is very much out of sight, out of mind. I hope I don’t sound kind of cruel by saying that.’* (OL, distant carer for parent).

OL’s own perception of the extent of his contribution to his father’s care was that it was insignificant compared to that of his mother who is the primary carer, even though OL performed physical and personal care such as dressing and showering for his father, as well as providing companionship and emotional support to both parents on his visits. OL described his role in the provision of care as ‘somebody that just organises the schedule of carers coming in’. OL’s account demonstrates that his experiences of caring at distance were a source of feelings of anxiety and a burden of guilt. Although he was involved in a number of aspects of care for his father, including emotional, personal and physical care during visits, as well as practical support such as scheduling visits from care agencies when providing care remotely, OL blamed himself for not doing more – a feeling shared by those who care for their older family members living at a distance (Baldassar, 2007; Sihto, 2018).

As evident from family carers' accounts discussed above, the concepts of care in the community and familial support evoked negative responses from both geographically proximate and distant carers. One of the main themes emerging from the interviews is the disparity between how community and familial support are imagined by commissioners of social care services and carers. Another theme relates to the complexities of the 'family dynamics' and tensions that arise within families when care responsibilities are negotiated and allocated. In order to explore further the complex interrelated aspects of community and familial support, the next section will be dedicated to the experiences and views of care in the community offered by respondents living with dementia.

6.4. The meaning of place to people living with dementia

Studies of the relationship between older people and place have spanned the fields of geographical gerontology and health geography, demonstrating the importance of place to older people's sense of identity (Wiles et al, 2012a; Rowles, 1993; Cutchin, 2017). Although person-place relationships have been theorised through a variety of approaches and models, including behavioural geography (Golant, 2011), phenomenology (Rowles, 2017) and relationality (Andrews et al, 2013), the common understanding of the interaction between the person in later life and place is that the attachment to place increases as people age (Gilleard et al, 2007; Cristoforetti et al, 2011; Wiles, 2017). According to Wiles (2017), older people are less likely to move than younger people as they become bound to place through emotional connections, family networks and identity historically intertwined with the social space of their local community as well as social connections developed over time. A sense of connection to place and accompanying feelings of familiarity and security are considered to be among the positive aspects of 'ageing in place' (Wiles et al, 2012a: 357). However, inevitable changes to body and mind engendered by the ageing process are seen as a force driving the renegotiation of older person's relationship with place and surroundings. Attachment to place experienced by an older person facing new challenges of ageing is not at all static but is continuously transformed through a process described as active ‘place reintegration’ (Cutchin, 2017: 218), producing a new sense of self and affecting relationships with others. The empirical analysis of ‘ageing in place’ experienced by people with dementia and carers who took part in the study has revealed a variety of processes in which the participants engaged to renegotiate their relationship with place.

One of the salient themes that has emerged from the interview data was that of profound and multiple changes to personal identity effected by the awareness of growing older, decline in health and functional capacity, and failing memory and cognition - symptoms of dementia. For example, one of the respondents living with early stages of dementia – PS made it clear during the interview that she disliked telling me about changes to her physical and cognitive health as, in her opinion, as a younger researcher I simply ‘would not understand’. PS felt that the challenges she was facing were unique to her as an older person, and it appeared that the topic raised negative emotions leading eventually to PS refusing to continue with the interview. The following excerpt illustrates PS’s belief that one has to be old in order to experience interactions with everyday objects in the same way as she did:

> *LO: So do you do most things around the house yourself?*
>
> *PS: Everything. It’s getting harder and harder.*
>
> *LO: Is it harder physically?*
>
> *PS: Well… you’ll find out when you’re old.* (PS, person with dementia)

It is possible that PS’s reluctance to talk about her physical and mental decline is a coping strategy she employed in order to continue living independently and caring for her husband who has severe health and mobility problems. Coping strategies initiated by older people in order to remain in place, even when circumstances become challenging, have been explored by scholars from the fields of geography and geographical gerontology (see Golant, 2017; Shank and Cutchin, 2016). Ignoring or denying one’s difficulties is one of the adaptive strategies to which older people often resort in order to cope with stressful life events. Other strategies employed by older people to exercise a degree of control over person-place processes embedded in the ageing in place experience focus on maintaining and building their ‘social infrastructure’ and negotiating ‘daily participation’ (Cutchin, 2017: 222) in a community life, coordinating it with personal abilities and needs. In PS’s case, social infrastructure that she had carefully negotiated and on which she relied when she needed help included proximate networks, such as her immediate neighbours and companions from the befriending service, and her remotely located ‘gang’ – her children who visited mostly during holiday periods. Of her relationship with her neighbours PS said:

> *‘Oh I’m alright. If I was stuck, next door would be kind. They’ve got a better garden than me so they’re always pulling my leg.’* (PS, person with dementia).

M’s approach to maintaining his social infrastructure and continuing to live in the place of his choice while facing a decline in his memory was based on accessing support from volunteer befrienders with visiting places in the local community, as well as supporting the running of activities in a day centre for people with dementia based in a local hospital. M fully accepted his diagnosis and was aware of the inevitable further deterioration to his memory and cognition:

> *‘It’s just this ‘can’t remember’ job, it’s awful. I can’t remember and … I struggle then, I struggle to try and put things in place.’* (M, person with dementia)

Yet, on his visits to the day centre M felt that he was in a better position than other attendees who used the service and compared himself favourably to other people with dementia:

> *‘It’s a bit disturbing because some of the patients, I automatically help them as best I can, the same as the teachers do, but it gets you down a little bit to see how bad they are, you know, and you want to do more for them.. I don’t mind that because it was helping them and that’s helping me, it’s Peter pays Paul, isn’t it?’* (M, person with dementia)

Comparing oneself favourably to others is described by Golant (2017) as another coping strategy employed by older people experiencing difficulties in order to continue to remain and age in place. It seemed that for M, supporting people in the day centre also offered a degree of confidence in his own ability to function better than others living with dementia, and added to his sense of being independent and in control. Thus, by actively investing his emotional and, at times, physical labour in helping others, and by remaining connected to everyday life of the community M was able to construct a positive sense of his own identity.

M’s other source of strong connections to place and community came from his engagement in the volunteer befriending scheme run by the case partner organisation. Scheduled regular visits to places of M’s choice with a volunteer befriender became a part of an important routine for M, who also descried the relationship between himself and the befriender as friendship. The befriender’s visits to M would often last for over half a day, as he would pick up M who is no longer able to drive because of the dementia diagnosis in his car and drive M to a meeting of a community group, taking place in the grounds of a local football club, to museums or M’s favourite pub:

> *‘LO: So what do you do when he [befriender] visits?*
>
> *M: Well we go to museums and places like that down town which is very interesting.*
>
> *LO: Is that something you like doing, going to museums?*
>
> *M: Oh yeah, yeah, yeah. I like, you know, the past, I like to look at what was yesteryear sort of thing, or many years ago. I like anything like that. And he’s very polite, he’s, well I’m even going to say he’s a little gentleman, yeah he’s a nice guy.’* (M, person with dementia)

The above exchange demonstrates, that through the caring relationship developed with the befriender and visits to places meaningful to M, he was able to preserve and maintain his sense of identity and autonomy. In addition to reinforcing M’s connections to place, the visits were a social experience shared with the befriender during which new memories and connections were formed. This finding echoes conclusions of earlier studies which highlighted that visiting places together, engaging in an ‘occasional co-presence’ (Bowlby, 2011: 611) and creating shared memories helped the person receiving care to maintain their sense of identity.

In another interview with a carer, WL who looks after her mother with dementia, the theme of a new person-place relationship facilitated and enabled by a third party – in this case the carer - also arose. Before WL's mother moved to WL's area from another city following the diagnosis of dementia, WL sought opportunities for voluntary work that would be suitable for her mother in the local area by making connections with voluntary organisations and church groups:

> *'What I'd done because I'd been planning that, I'd been thinking before that so I got things in place like voluntary work and that, because I knew I'd be at work and I thought 'I don't want her sitting in the house all day on her own.' So I then had got her some voluntary work in place, so when she did come down she was able to start that pretty straight away.'* (WL, carer for parent)

It can be said that WL's awareness of the importance of not only material but also social integration in place, and the resulting arrangements providing an enhanced daily participation in the life of the community to her mother possibly mitigated against the trauma of the transition. The move undoubtedly engendered a certain extent of identity renegotiation for WL's mother who transitioned from living independently in a spacious house in the south of the country to a sheltered one-bedroom accommodation in a northern city. Thus, WL acted as a conduit to opportunities for constructing a new 'social infrastructure' (Cutchin, 2017: 222) for her mother, pre-empting and facilitating her mother's transactions with the new place.

In the course of the interviews, it became evident that proximate family members played a key role in the successful place integration for people living with dementia. Those interviewees whose family members lived close to them considered themselves to be very 'lucky' compared to those whose families lived remotely, and often expressed feelings of gratitude and pride in such arrangements. An interview with three women – KS, VA and WB living with early stages of dementia from the same locality, with family members living nearby, evidenced their sense of deep connection to the area where they could rely on their children's help and support:

> *'WB: This lady has got her son next door to her [pointing at VA].*

> *VA: And me daughter. How lucky I am!*
>
> *WB: Well I’ve got C, me daughter, she comes if there’s anything wrong.*
>
> *KS: As far as I’m concerned it’s [lifeline box] worth every penny, I don’t even know what it costs because my daughter attends to all my financial things and so I don’t know what it costs, but whatever it costs, it’s worth it.*
>
> *WB: Yeah my daughter works at [hospital], she is a staff nurse but she’s not on call because she’s working all the time… She’s coming tomorrow to do my housework, she’ll clean up for me and do it tomorrow.’* (WB, VA, KS, persons with dementia)

The women’s feelings of contentment and security at living in close proximity to their family members contrasted to their opinions about moving to residential or nursing accommodation. All three expressed highly negative views about living arrangements in residential care highlighting the lack of autonomy and independence as major concern:

> *‘LO: And you would prefer to live in your own home for as long as you can?*
>
> *WB: I couldn’t live anywhere else. They might as well cut me legs off. I couldn’t live in a home, could you?*
>
> *VA: No.*
>
> *WB: Could you [to KS]?*
>
> *KS: No, no way, no.*
>
> *WB: No I couldn’t do it.*
>
> *KS: My daughter’s promised me, she said ‘You’ll never have to go into a home’.*
>
> *WB: No, no.*
>
> *KS: We’ll sell both houses, get something bigger’.* (KS, WB, VA, persons with dementia)

The clear sense of belonging and feelings of attachment to one’s place expressed by the participants of this research echoes conclusions of other studies (Gilleard et al, 2007; Koss and Ekerdt, 2016) which found that such feelings strengthen with age. Furthermore, supporting the findings outlined in the paper by Koss and Ekerdt (2016), this study has found that social relationships with family members and availability of family assistance are the key factors in deciding to stay put and to age in place.

Through the expressions of choice regarding living arrangements and where to age the women reaffirmed their identities as independent, autonomous beings enjoying fulfilling lives and strong social and emotional connections to their families and the locality where their independent living choices can be exercised. These expressions of a sense of this particular identity contrasted with the living and care arrangements that were actually in place, characterised by the women's deep reliance on family members for a range of essential tasks – from cleaning their houses, to health monitoring and looking after their financial affairs. This type of autonomy that I have described as 'enabled autonomy' was a key condition for the women's ageing in the place of their choice. This finding agrees with other studies (see Gilleard et al, 2007) which highlighted the importance familial support plays is growing old in place.

6.5. Ageing in place – ageing at home

The theme of growing older in one's own home was one that emerged from all interviews with people with dementia and carers. It was also a recurring theme in interviews with professionals, including members of staff employed by the case study partner running the Befriending Scheme, and various stakeholders, including those representing social care commissioning bodies. Whilst the participants living with dementia and carers described their experiences in a variety of ways, often without explicitly using such phrases as 'ageing at home' and 'living independently in own home', the responses from the professionals and stakeholders almost universally contained the phrase 'staying in one's own home for as long as possible' or variations of thereof, often accompanied by discussions about independence and personal responsibility for own health and care, as the excerpts below demonstrate. These views, expressed by the professionals who participated in the study, reflect the wider shift towards the responsibilisation of care, discussed in chapter Five of this thesis, as well as in geographical and sociological literature on care (Milligan, 2000; Fine and Glendinning, 2005; Trnka and Trundle, 2014)

> *'They [older people living with dementia] want to stay at home, they want to stay independent.'* (HR, Project Manager)
>
> *'And that's what the [technology roll-out] programme was about, taking great technology things and helping the self-care, the self-management and the self-service agenda in care, in health to move forward at pace.'* (TS, CCG)

Although the latter quote was presented by the respondent in the context of describing a region-wide drive to introduce and embed assistive technology products and services in health and social care provision, which will be further discussed in chapter Seven, it is the second part of the quote, relating to the agenda around personal responsibility for own health and care, that is of relevance to the discussion of ageing at home. Recurring calls 'to take responsibility' for ageing well in own home voiced by professionals, discussed in chapter Five, and the allusions to an existing 'agenda' are evidence of the wider shift in the conceptualisation of rights to and responsibilities for social care. The change in the place of care provision from large institutional settings to community and home has placed the responsibility for care of older people on the individuals themselves and their family members (Milligan and Power, 2010). While my study has found that ageing at home was the most desirable residential option for the participants with dementia as well as the professionals, the former require adequate support and resources to be able to do so, while the latter pursue efficiency savings to the diminishing social care budgets. Thus, the desire to age well at home with support is incompatible with the policy drive aimed at cutting public resources to care provision. The two quotes below – from a professional who is also a carer at distance for his parent with dementia, and a person with dementia, provide an example of how views on ageing at home converge, while also simultaneously revealing the divergent beliefs on which these opinions are based:

> *'… they [the parents] want to stay in their own home at the moment. It's much better for them, you know, I think it's much better for the state because it's cheaper and that's where they want to be'.* (OL, stakeholder and carer)

> *‘They do say if you’re in your own place you live longer than in these homes [care homes], don’t they?’* (WB, person with dementia)

It is clear from WB’s quote that her preference to stay at her own home is influenced by her fear and dislike of institutional settings which, she believes, negatively affect one’s longevity rather than by any considerations relating to savings to the public finances potentially made by her continuing to live at home. Echoing views of participants with dementia from previous studies (see Lee et al, 2013) who felt that their needs would not be met if they moved into residential care, WB was not alone in her aversion to the idea of moving into an institutional setting. Indeed, this was a salient theme in the interviews with other people living with dementia. Among their concerns relating to not being able to age in one’s home resulting in a move into an institutional setting were perceptions of institutions as places with highly restrictive regimes, where day-to-day activities such as gardening and taking care of pets were not available:

> *‘LO: K, why is it important for you to be in your own home rather than in one of these places [a care home]?*
>
> *KS: Well to start with I’ve got my dog and she’s a companion to me, and I can’t imagine life without her now. And I like my bit of gardening, tootling around in my garden, this sort of thing.’* (KS, person with dementia)

The above quote shows that for KS the attachment to her home is, in part, expressed through the pet’s companionship and her love of gardening (see Milligan et al, 2004). These two aspects were mentioned by a number of other respondents living with dementia in their accounts of everyday domestic practices. Participation in gardening in particular was usually discussed when the respondents described their physical and cognitive health in the context of continuing to live at home. Notably, the respondents’ narratives about living at home never seemed to include the description of a home as a static, fixed secure place, for instance as a ‘refuge’. Rather, when asked to talk about living in own home the interviewees tended to describe how they performed their daily routines, including gardening, cleaning and cooking – all of these activities constituting what has been theorised as the ‘making’ of home’ – a process flowing over time through which the domestic space is continuously produced and reproduced (Bhatti, 2006: 321). For instance, when asked to describe what helps him to manage to stay in his own place, JK said:

> *'I am really happy in a way that I'm here in my own place… Well, I think I have a good life because I start my life in the morning, I get out of bed and I go to the bathroom etcetera, and I start to cook my breakfast. I have a good breakfast, I have a good lunch and I have a good evening meal. I couldn't want for anything else.'* (JK, person with dementia)

While in this instance JK's engagement in the 'lived realities of home' (Brickell, 2012: 226) gave him a feeling of satisfaction, his accounts of other practices of the everyday domestic life were less positive, as his declining physical and mental functioning became more pronounced – views echoed by other participants living with dementia. Difficulties with gardening activities appeared to be one of the key indicators perceived to herald physical and mental decline. For example, JB's account of his life in a place where he and his family had moved about fifteen years previously entails his views on the physical changes he has experienced resulting in the reduction in participation in gardening:

> *'So yeah … we like it here and we're glad we did it [moved] cos, you know, there's plenty of room too and it's all different, everything, the gardens are different. And it goes right down to the wood down there. But when I first came I was a lot fitter than I am now and a lot younger.'* (JB, person with dementia)

At the time of the interview JB said that he didn't do anything in the garden and that he and his wife have had to pay someone to maintain it - 'we have got a bloke who comes'. Previous studies have found that gardening activity can be a source of please and provide a sense of achievement and satisfaction to older people (Milligan et al, 2004). At the same time, physical limitations experienced by people in later life mean that in order to continue to enjoy the activity older people increasingly require support. If such support is unavailable, the garden can become viewed as a burden rather than a source of enjoyment. With the help from a professional gardener employed by JB and his wife, JB still was able to maintain pride in his immaculate garden and retain as sense of satisfaction with his place.

M, who used to be a keen and proud gardener felt frustrated that he could no longer continue to engage in one of his favourite leisure activities, as the below exchange between M and his wife and carer V shows:

> *‘M: Everything that I do works well, you know what I mean, anything, in a garden or anything like that, because it’s beneficial to yourself.*
>
> *V: He used to love the garden, M, but basically now [sighs].*
>
> *M: Yeah, sometimes it’s umm, it’s, it’s, but I think that’s physical.*
>
> *V: It’s part of your Alzheimer’s.*
>
> *M: You know, yeah. Put that down to that. Alzheimer’s.’* (M, person with dementia, and V, his wife and carer)

JK held strong memories about his favourite gardening activities and plants that he used to grow, and talked about them with a sense of sadness and nostalgia:

> *‘Well if I was pretty mobile, I’m not so bad really but there’s times when I am bad, but I was a mad gardener, yes oh I used to grow some beautiful chrysanths! But since the old legs have developed and one thing and another, and I don’t say mentally I, I can read things and remember things and know what things are, but I’m not as active, I give way to age.’* (JK, person with dementia)

The effects of the inability to maintain the garden on the person’s identity have been described by some scholars as ‘acutely depressing’, engendering the feelings of frustration and powerlessness, for instance in cases where the individual had to employ someone to perform the tasks previously regarded as easy and enjoyable (Bhatti, 2006: 333). Thus, the process of the ‘making’ of home turns into that of ‘un-making’ resulting in the feeling of ‘not being at home’ (Bhatti, 2006: 334). In the case of the three men quoted above, the cessation of participation in gardening did not seem to have a profound impact on their feeling of being at home, as they found other ways to maintain their identities rooted in independence, some of which were discussed above in section 6.3. (on autonomy). The instabilities of being in place brought about by the advancing dementia and failing physical health were compensated for through new adjustments and new ‘anchors to identity’ (Rowles and Ravdal, 2002: 82). In M’s case these adjustments came in the shape of volunteering in the local hospital’s day centre thus necessitating a transition from a tough businessman and a publican who once ‘had to knock one fellow out’ to a caring companion to people with later stages of dementia who is ‘terrified to lift [them]’ because he is ‘too strong’:

> *‘Well again like I’d be terrified to lift or try and help them [people with dementia attending day centre] because I’m too strong, I don’t know when I’d be hurting them or not, yeah.’* (M, person with dementia)

JB continued driving to the beach with his dog and maintained his social connections in the community of dog walkers, while JK savoured meeting new people during his outings with the Companions service:

> *‘And when you get out amongst strangers and you listen to them and don’t interrupt them, I find it very very interesting that they can take you in a conversation to various places.’* (JK, person with dementia)

Inside the house, the sense of ‘feeling at home’ was often disrupted by what Blunt (2005) theorised as ‘disjunctures between idealized designs and the embodied practices of everyday domestic life’ (Blunt, 2005: 507). These ‘disjunctures’ become most apparent as the decline in physical and cognitive functioning progresses. Golant (2017) believes that the causes of the disconnect could be found in the design of dwellings intended originally for younger consumers, posing ‘usability challenges’ for older people (Golant, 2017: 192). Indeed, a number of interviewees highlighted their daily struggles with various elements of design within their homes describing in detail particularly challenging areas of the homes’ micro-geographies. For example, MO stated that she would have moved from her house which she found difficult to maintain if it had not been for her pet cat:

> *‘Well, I've got a cat, if anything happens to him I'd like to move.’* (MO, person with dementia).

Other areas of MO’s home – the bathroom and the kitchen presented further risks. During the interview MO mentioned that she had not been able to have a bath for a year as she was not able to get out of it. MO had a shower installed in her bedroom because, she said:

‘if you stood in the bath you were right in front of the window, so that was no good, you see.’ However, this did not improve the safety of MO’s environment as she kept tripping out of the shower. She was therefore considering having her bath remodelled, however a large financial cost of the work was a source of worry for MO. There were two steps leading into the kitchen which presented a constant risk of falls; indeed not long before the interview took place MO had tripped over the steps and fell: ‘[I] just sort of slipped, I don't know what it was. It was only the once though’. It was evident that these ‘disjunctures’ and struggles affected MO’s emotional attachment to her home eroding her affective ties to the place. During the interview she mused about where she could potentially move recounting her children’s living and housing arrangements:

> *‘Where would I move to? Well my daughter's hasn't got room for me anyway. She's got a canal boat, she wants to go and live on that! I can't see me living on a canal boat.’* (MO, person with dementia).

MO’s concerns about being able to stay in her own home and independently manage the fabric of the dwelling were shared by participants with dementia from previous studies (Means, 2007; Wiles et al, 2012). While for some staying put and ageing in place becomes difficult due to health limitations and other options are explored (Means, 2007), others respond to adversity by drawing on physical and social resources available to them, such as keeping busy, maintaining social connections, and engaging in physical activity such as gardening in order to remain in place (Wiles et al, 2012a). MO’s case is the example of the latter: eventually, having explored the idea of moving to a new house MO concluded that despite the difficulties she experienced on a daily basis she was not willing to leave the place, which held fond memories. It seemed that the strong affective ties to the place developed over the years outweighed the challenges of negotiating the risky micro-geographies of the dwelling:

> *‘I quite like living where I am. I don't know whether I would like it anywhere else. I don't know really whether I would. I DO like, I mean it's LIGHT in here, isn't it? And I'm near the village, aren't I? It's a bit of a step coming up the road if you're walking but it is nice here. I don't think I'd, I mean I keep saying I would like to move but I don't know that I would find anywhere that I'd like as much. I mean I say it but*

> *WOULD I? No, no. There's a lot of memories here so yes.* (MO, person with dementia)

MO's decision to stay in place was additionally strengthened by a coping strategy expressed concisely in the following sentence:

> *'And you can't have everything in life anyway. Nobody has everything in life.'* (MO, person with dementia).

A strong illustration of the 'usability challenges' experienced in place by people with dementia and carers was offered by PD's circumstances. PD cared for his mother with advanced dementia at her small two-up-two-down terraced house. As his mother's mobility further declined and she could no longer use her bedroom on the top floor of the house, PD began to explore adaptations. Echoing Golant's (2017) point about the unsuitability of poorly designed older dwellings to the needs of older persons, PD said about his and his mother's house: '…We are a Victorian terraced house. They weren't built for people to get ill.' PD's attempts to make alterations to the living space in order to enable his mother to continue to remain and receive care at home were not successful, as the options for new design were neither suitable to his mother's needs nor to his needs as a carer:

> *'So two alternatives were to put a straight up and down lift… She sleeps in the front of the house, I sleep in the middle, they were going to turn my room into a shower room, but there was nothing said about where I was going to go. Then the other alternative was for downstairs to build up an extension, but as people at [hospital] said she would have been living on a building site. Every day would have been a new day, you would have to have explained to her'* (PD, carer).

The impossibility for PD and his mother to maintain her ageing in place in part due to the profound disjunctures between her changing physical needs and cognitive capacity and the design of the house was a contributing factor to her leaving home and entering residential care. As PD put it himself:

> *'I would have been prepared to care for my mother until the day she died but unfortunately we [the family] couldn't provide the facilities for her.'* (PD, carer)

As a carer for her husband with later stages of Alzheimer’s disease, BR faced similar challenges. Echoing PD’s commitment to caring for her family member at home, BR explained:

> *‘Because basically if I could have had the proper support I’d have had him [husband] home.’* (BR, carer for spouse)

While her husband remained physically healthy, his mental capacity decline meant that he needed a high level of support with performing everyday domestic practices, including personal care.

> *‘I couldn’t get him up the stairs, he stopped climbing stairs. I couldn’t, my bathroom is only tiny, at one point you could get him to stand in the bath to shower him, that all went.’* (BR, carer for spouse)

BR and her husband’s struggles were compounded by the unsuitability of the physical form of the dwelling to her husband’s needs, which could not be met even with adaptations available to them at the time:

> *‘They [Occupational Therapy Service] gave me a bath board which went across the bath for him to sit on but how does he, when you said ‘Lift your leg up, D,’ he doesn’t know what his leg is. Even if you’re tapping him to try and pick they become dead weights… But it was hard work and he’d had a couple of falls in the bath. So that wasn’t good.’* (BR, carer for spouse)

Eventually, BR described how D’s further deterioration resulted in him being washed by care workers in the front room of the house, which significantly altered the micro-geography of the home, and had a strong negative impact of BR’s ability to cope with her caring duties. D finally left home and moved into a residential care setting after his behaviour towards D became violent which she said was very much ‘out of character’ for him:

> *‘LO: So you wanted him [D] to stay in his own home but it wasn’t possible?*
>
> *BR: No. But then he started to get a bit violent and that didn’t help.’* (BR, carer for spouse)

Previous studies have shown that carers of people with dementia experience high rates of stress, distress and psychological illness (Burns and Rabins, 2000; Mahoney et al, 2005). Without adequate support, in particular with dealing with the changes in the behaviour of the person with dementia, carers physical and mental health deteriorates which results in them not being able to continue to provide care leading to the move into residential care for the person with dementia (Burns and Rabins, 2000; Etters et al, 2008). As BR's quotes above demonstrate, the support she and D received was not adequate to meet their changing needs resulting in D being placed in a nursing home. This further contributed to BR's ill mental health as she began to experience the feelings of guilt as well as developing anxiety caused by the financial burden of paying for regular multiple taxi and public transport journeys to the nursing home.

The views of people with dementia and carers presented in this study and the emerging themes indicate that while it is the preference of older people to age at home, challenges posed by dementia, including declining cognitive capacity and memory, introduce significant barriers to successful ageing in one's own place. While respondents living with earlier stages of dementia were able to continue to live at home by renegotiating their identity within place and adapting to new challenges, those with later stages could not always do so, even when cared for and supported by family members. As needs increased, for some, home became a site of struggle and conflict. Identity reshaped by memory deterioration and the loss of cognitive ability often led to the changed relationship to home space, objects and people, creating new micro-geographies of the home. BR's account outlined above of her attempts to continue providing care for her husband at home demonstrates the transition of their familial home from a place of closeness and intimacy to that of exhaustion and despair.

6.6. Concluding remarks

In this chapter I explored some of the key ways in which providing and receiving dementia care in the community has been conceptualised. Whilst care in the community is presented by policy makers as the best option for those living with dementia (Department of Health, 2015), accounts of carers of people with dementia present a picture of social isolation and family tensions, including between those who live proximately and at distance. By bringing to the fore the experiences of proximate and distant carers, I hope to contribute to the scholarship on the impact of care in the community on families (see Baldassar, 2007; Sihto, 2018). In this chapter I also presented the analysis of accounts presented by people with dementia of ageing in the community and at home. Whilst these accounts demonstrate that people with dementia cherish their autonomy and pride themselves in living independently, they nevertheless place a high value receiving support from family members living nearby. I thus introduce a concept of 'enabled autonomy' which appears to essential to people with dementia being able to 'age in place.

Chapter Seven will build on these findings in its examination of technologies of care and how these shape understandings of what constitutes care and care practices.

Chapter Seven: Perspectives on technologies for care

7.1. Introduction

This chapter seeks to understand the role of care technologies in the provision of dementia care. After examining the perspectives of people with dementia and carers providing and receiving care in place, I analyse their views on ageing in place supported by technological solutions. Section 7.2. presents a mixture of views on technologies from professionals, carers and people with dementia. While the professionals' enthusiasm relating to 'technologisation of everyday life', as theorised by Brittain et al (2010: 273-274), is evident, the perspectives of carers and people with dementia present a more critical view of technologies, informed by their interactions with a range of items and systems. Drawing on interviews with people with dementia, Section 7.3. argues that everyday household technologies and simple home adaptations have a more pronounced impact on the lives of people with dementia than digital technologies, such as laptop computers, tablets and cameras. In section 7.4. I explore reasons behind technology adoption and abandonment by people with dementia and carers, and argue that carers' own confidence and skills relating to technology use either promote or inhibit technology use by people with dementia.

7.2. Perspectives on technologies of care from professionals, carers and people with dementia

Although the definition and description of assistive technologies were discussed in chapter Two (literature review), it is necessary to revisit them in this section in order to clarify the classification of technologies I encountered in the participants' homes. In their analysis of older people's negotiations of health and illness, Joyce and Loe (2011) argued that older adults, whom they describe as 'technogenarians' regularly engage with a wide range of everyday technologies, including pharmaceutical products, phones, walking aids, stairway railings, adjusted toilet seats, and other multiple designs and modifications within their homes. Older people with dementia and their carers interviewed for this research used a similar array of assistive technologies as well as some environmental design modifications, such as handrails located nearby doors and in bathrooms. Loe (2010) in her research into the use of everyday technological tools such as slow cookers, gardening tools and televisions by nonagenarian women argued that through such simple everyday technologies older women were able to 'create meaningful lives and maintain health' (Loe, 2010: 142). Loe found that through adaptations of everyday technologies to their changing needs, older women were able to stay connected to their social networks, maintain their physical wellbeing and intellectual growth. Thus, the author concluded, everyday household technologies, also classed as 'low tech' should be recognised as assistive or health technologies (Loe, 2010: 143).

Discussions relating to the use of technology in supporting people living with dementia with research participants revealed varied perspectives on the role of technology in dementia care. In interviews with professionals and staff at the case partner organisation, assistive technology was presented as a mechanism supporting the current policy drive for efficiencies in care provision, as discussed in section 5.2. Technological solutions were also considered by professionals vital in supporting older people to 'age in place' – to remain in their own homes for as long possible, to prevent hospital admissions and to reduce numbers of older people moving into residential care. For instance, OL who works at a hub of local health, innovation and technology development organisations described the role of technology in care as follows:

> *'Obviously a lot of health care is delivered in the community already.., but we need to do things around that make sure that people that go into hospital can move back out of hospital into their own homes and live there safely. And also … by providing technologies we can, hopefully, prevent people going into hospital for as long as possible than using more expensive health care resources.* (OL, professional)

OL's quote touches upon a number of areas where technology for care is promoted by policy makers and practitioners as a means to achieving what some of them have termed 'a successful old age' (see for example Peel et al, 2004; Sixsmith et al, 2014). Firstly, technologies such as telehealth and telecare, are positioned as instrumental in maintaining and driving further deinstitutionalisation of health and social care (Milligan et al, 2011). Secondly, in the context of care provision located away from institutions and within the home, the focus is often primarily on the safety of the care recipient. Maintaining safety and security, according to Gibson et al (2019), may be the main priority from the perspective of care policy makers, but less of a concern for the care recipient living with dementia and his or her carers, who may prioritise other needs more highly. Thirdly, by positioning technology use as key to prevention of hospital admission, OL echoes the dominant discourse of self-management and individual responsibility for own health and wellbeing underpinning recent policy development (Mort et al, 2013).

Other professionals interviewed for the study shared OL's anticipation of the reductions in the use of expensive publicly funded health and care services achieved through technologies of care. One of the sub-themes that emerged from the interviews was the consensus among the professionals that the current model for health and social care has to undergo substantial changes in order to maintain sustainability. Some professionals, such as UJ, a senior manager at the case partner organisation, called for changes to 'the way things are' in order to achieve fiscal efficiency:

> *'I think there's enough knowledge that we can't carry on the same, I think the way, and we've been saying that, and yet we still seem to be carrying on the same. I think the investment [into a local assisted technology project] from the [governmental department] … is an acknowledgement that we've got to do things differently… I think there's an understanding 'We can't carry on the same'. Technology, if it works right and it's done properly, can just change the face of the NHS, of social care as it stands.'* (UJ, Head of Services)

UJ considers technology a catalyst for transformation and greater efficiency of health and social care services reflecting concerns of professionals interviewed for the study about the ability of the state to deal with problems of the growing ageing population (Lupton, 2014). In addition to efficiency savings, some professionals believed that care technologies could be crucial in alleviating the problem of care staff shortages. For instance, HR, a project manager at an agency whose role entails creating connections between health sector, research organisations, academia and industry, highlighted what he felt would be a key function for care technology in the provision of care services at home:

> *'We need to change what we're doing to generate, to get the efficiencies that we need. We haven't got the staff, when you look at domiciliary care, we haven't got the staff that we can recruit to do it. And there are other areas that are even worse that Liverpool City Region, so down in Cornwall, for example, where we've got a really ageing population… they're looking at robots really seriously because they don't have the staff.'* (HR, Project Manager)

For HR and other professional stakeholders in the study, technology offers a potential solution to the problem of care staff shortages and increasing demand for services, a finding highlighted by previous research into technologically supported care (see Milligan et al, 2011). Participants in my study held a range of views on the relationship between care technologies and human carers: firstly, as evidenced by HR's quote above, care technologies were identified as a viable alternative to human care workers. HR pointed to domiciliary care services as an area of service provision that would benefit greatly from care technologies. Having 'butler robots' or 'robot carers' was discussed by professionals, such as HR, as well as technology developers as desired care arrangements for their own later lives. For example, a director and founder of a technology company, which has successfully designed and implemented a number of technological care products, described his vision of the near future where technology will replace many roles currently performed by humans in a range of sectors, including health and social care:

> *'Government are also pushing for efficiencies in the age of austerity, you're seeing cutting budgets in the National Health Services, in Local Government Services, and the thinking is that some of those traditional people-delivery services will be replaced by technology. I don't think that's particular to that industry [social care], that's happening in every sector, so I'm sure in 20 years' time there'll be robots doing some of the people's jobs outside the window now.'* (TD, technology developer)

The idea that health and social care sectors will simply follow the trajectory of technology replacing human workers that is already evident in other industries was echoed by other technology developers. These developments were perceived as problematic on a wider societal level, expected to have a negative effect on rights of workers, and linked to the broader economic agenda of austerity pursued by the UK government. ZM, another technology developer working in the field of assistive technologies for health and social care explained:

> *'The fact is that people who work in car factories now are looking after the robots. The number of working, of skilled working class jobs are [sic] reducing and that's going to bite into middle classes soon as well. But you know, that's a problem for all society not just for health and social care system. The problems with technology - assistive technology- are the same problems all society faces.'* (ZM, technology developer).

Nevertheless, despite anxieties about large-scale changes that technologisation of health and social care is expected to engender, some technology developers welcomed the possibility of having a robot personal assistant:

> *'I would love that robot now! As a younger disabled person I want my robot butler now. I want my robot carer now. I want to be carried up the stairs by a bloody robot immediately. Exosuits are going to come and robot butlers are going to come. We are going to have baby steps. I want to work on, you know, one of the things I want to work on in the future is robot butlers.'* (ZM, technology developer).

Positive views of care technologies – future and existing – were echoed by a number of professionals, including those working in the social care delivery sector. For instance, UJ described an environment of 'an expectation' where those receiving health or care services should demand that these are supported by technologies similar to other areas of everyday life, such as management of personal finance through online banking:

> *'We grow up and there's an expectation that we use technology, so there's an expectation that I can go and do online banking, or there's an expectation that I can Skype somebody and see them even if they live three thousand miles away. So why can't there be an expectation that I will use technology to support my health? So there's an expectation, I feel people are ready and waiting, you know, ready for*

> *it. It’s there, we just need to make more of it. It should be basically, you know, you can Skype your GP, just even using that as fundamentals, and I think there will come a point where people will go ‘Well why isn’t this happening? Why do I have to take three hours out of my job to go and see the GP when I’ve got, you know, I can Skype everybody else, why can’t I do this? Or why can’t I monitor myself at home?’* (UJ, Head of Services)

For UJ and other professionals in this study a technologically mediated virtual consultation with the GP was seen as preferable to an actual visit to the surgery. Communicating via Skype for purposes of health care was considered by the respondents in this research to be a valuable time-saving technique for the professionals leading busy, socially rich lives. Echoing UJ’s reflections about the use of communication technologies such as Skype in health care, OL discussed the idea of having a choice to either use Skype or to travel to the surgery to see his GP:

> *‘I think Skype can make a difference, you know, if I, put it this way, if I could do a GP appointment via Skype I’d be pretty happy because I wouldn’t have to spend the time. For me as an individual if I could just, you know sometimes it’s quite nice to go see a GP, but sometimes if I could just make a phone call and say ‘Well look I’ve got something that doesn’t really require much investigation … can you just book me in for a minor surgery?’ That would work really well. I think Skype and stuff … definitely does have a place in healthcare.’* (OL, professional and distant carer)

Both professionals quoted above did not feel that face-to-face contact with a health professional unmediated by technology was necessary for their physical or mental wellbeing. Using Skype as a medium for obtaining medical advice and conducting a patient-medical professional relationship was preferable to travelling to an appointment in ‘real’ space (Longhurst, 2013: 667). However, both interviewees recognised the high value older people place on face-to-face contact with health and care professionals. Although real time visual images of health professionals conducting the consultation would have been available to the respondents’ parents via Skype, they potentially would have been disorientating to people with dementia, and seen as ‘uncomfortable and restrictive’ by carers (Longhurst, 2013: 674). OL, for instance, talked about his mother, who is the primary carer for his father living with dementia, continuing to visit her GP's surgery and local shops despite difficulties with mobility, rather than move to telephone appointments or use the Internet to pay bills. In OL's opinion, these visits helped his mother to alleviate social isolation that she had begun to experience as her husband's needs for care increased. In this case, OL felt technology use could be detrimental to the carer's mental wellbeing and could further exacerbate the feelings of loneliness and isolation:

> *'I say to my mum sometimes 'Why are you going to the paper shop two miles away to pay your bill, why don't you just give them a phone and pay it over the phone or why don't you find some other route to pay the bill without having to go there, because it's a complete nightmare to get to, you know? Also why can't you just phone up the GP, why do you have to go and see them?' And … I think my mum does feel, you know, because my dad has dementia, she does get socially isolated.'* (OL, professional and distant carer)

The idea that some of the technologies used in care can cause social isolation in family carers and those receiving care was expressed by professionals, technology developers as well as people with dementia and carers, and became one of the more salient themes derived from the interviews.

Notably, contrary to findings reported in previous studies ,which have shown that some policy makers and practitioners believed that automation of many care functions would result in seamless services and empowerment for patients (see Mort et al, 2009), professionals in the current study demonstrated a more nuanced approach to the issue of human carers being replaced by technology packages, such as telecare. In their study of 'telepatients' Mort et al (2009: 23) described divergent views of 'patients' using telehealthcare technologies and the 'official talk' of professionals, with the former expressing fears that technological solutions will substitute human carers and personal interaction. Service users preferred to see an approach characterised by 'hybridity' – a combination of telehealth services and support provided by human carers, 'a bit of both'. Meanwhile, professionals' views were more aligned with the 'all or nothing' vision in their pursuit of greater efficiency (Mort et al, 2009: 23).

For instance, in this study, a senior member of staff from the city’s clinical commissioning group outlined his vision of the combined roles of human and technologically supported care as follows:

> *‘I think we’re a long way from removing people to deliver domiciliary care… We might have machines to help us do care planning or care management, to help us find out what’s in the community to plug people into, but I think you still need that personal touch to do the mixing. But technology can help, it can assist, it can make things more efficient and joined up.’* (TS, CCG)

While TS believes that technology is crucial to achieving seamless services and efficiency savings in health and social care, he nevertheless recognises the importance of human interactions working alongside technologies, an approach reflective of the concepts of ‘hybridity’ and ‘heterogeneity’ in care practice described by Mort, Finch and May (2009). Similarly, other professionals interviewed for the study reported that older people receiving care saw unmediated, face-to-face contact with carers or health professionals as essential, while elements of care provided solely through technology packages were regarded as superfluous. For example, SMA, a senior manager at the case study organisation offered accounts of older users abandoning health-monitoring technologies and continuing to visit health professionals in person. According to SMA, despite understanding the benefits of technology which included remote monitoring of vital signs, such as blood pressure and blood sugar levels, and communicating those to the GP via video conferencing, community dwelling older clients engaged by the service did not adopt the technology:

> *‘And that person [participant in the trial], his answer was, ‘Well we wouldn’t [use technology] because we like to go and see our GP.’ So it’s not that the technology was wrong, it’s not that it didn’t reach out to people, they could see that it was a good product but still, even in spite of that, they’d just prefer to go and meet [with the health professional] face-to-face.’* (SMA, Senior Manager)

Furthermore, others believed that without human support, technologies may reduce an older user’s quality of life, or even lead to a situation when the life of an older person living alone and relying on technology may be endangered. For instance, DM, a social at the case partner organisation rexpressed concerns relating to the use of a telecare package whose main purpose is to alert a member of staff at a monitoring call centre if a person has a fall:

> *'So it's a hindrance in as much as if the care is solely reliant on that Lifeline button, and if that person doesn't understand how to use that then there is no other backstop for that. You know, there's no human contact, so that person could essentially be lying there for hours on end and not get anyone checking upon them, because everyone is relying that the Lifeline button is going to work.'* (DM, Social Worker)

DM's quote corroborates findings of previous studies outlining similar concerns expressed by professionals, older technology users living with dementia and carers. For example Brittain et al (2010) found that the effect of technologically delivered care performed without human interactions was thought to be potentially disabling rather than enabling. Discussing technologically supported care balanced between human contact and technological input, DM raises the issue of over-reliance on technology. Telecare systems, such as the package to which DM refers, require an active participation of a carer in supporting such arrangements as charging batteries, ensuring the person with dementia wears pendants or carries fall detectors, carrying out maintenance checks and organising payments for the equipment and subscription charges.

DM's anxiety about the exclusion of a human carer from the complex network of telecare is consistent with previous studies of telecare use. For instance, Gibson et al (2019: 14) have found that carers and people with dementia who use telecare services felt that the system was set up to 'designed out' the carer with the purpose to encourage individuals with dementia to take a more pronounced role for their own care. Such design solutions, mediated against adoption of technology by users underlining the central role of informal carers within the networks supporting the person with dementia. The progressive nature of the condition means that the carer's role as a mediator between the person with dementia and technologies changes over time. As the individual's needs become more complex, the carer has to readapt and renegotiate care technologies in order to continue to maintain existing care routines. For instance, a study by Lorenz et al (2019) concluded that at a moderate to severe stage of dementia the use of technology by the person with dementia decreases while the carer becomes a more active user. This is echoed in my research as family carers often initiated technological interventions through researching care technologies on the Internet, negotiating the inclusion of a telecare system in the care package with social workers and health and care professionals, organising installation and purchasing items or obtaining them following a needs assessment by an occupation therapist. For example, WJ who cares for her mother living with an advanced stage of the Alzheimer's disease described how she and other family members learn about a home monitoring system that was installed in their mother's flat to enable her to continue living independently. The learning process involved a number of elements – from creating an online account to physically installing sensors around the apartment - steps that WJ's mother was unable to initiate or complete independently:

> *'When we had an installation of a whole system, the sensor system in the apartment, yes they showed us how it works because it was on a website, you have to have a log-in etc, etc. So I logged in and they showed us how to use the website to understand how to set it up. The sensors, how you want to look at the sensors, the times - and so some of it was training, some of it was self-explanatory. So it's just like 'Here it is, here is the product' and we worked it out ourselves, read the box and implemented it.'* (WJ, carer for parent)

It is clear form JW's quote that the technology installation process required the user to have at least some understanding of digital technologies and to be a confident Internet user. WJ's mother's advanced dementia meant that not only she would have been unable to install technology independently but also, more significantly, she would not have been able to understand the purpose of the telecare devices, how they work and how to maintain them. In addition, JW stated that in her opinion, the monitoring system did not have any positive impact on her mother's ability to live independently because 'she [mother] was just too far down the line with her dementia'. Other participants in the study talked about difficulties experienced by their family members with dementia when they tried to use even such well-established technologies as wheelchairs and recliners. For example, CA who cares for her husband described how she had to take on a more active role in operating her husband's devices as his needs changed:

> *'CA: Yes, he [husband] uses the wheelchair but I have to push it, cos he can't push it himself… So now I bought a special chair for him, it reclines and if you press a button, it comes up.*
>
> *LO: And do you have to press the buttons?*
>
> *CA: Yes, I have to cos he does not press them, yeah, he can't press… Sometimes, you know, if he gets up, it's because I press the thing to lift him, it comes up, slowly. He thinks he's doing it but he doesn't cos I'm doing it and he stands up then, which is good.'* (CA, carer for spouse)

CA's experiences of adapting the use of everyday technologies to new challenges presented by her husband's changing needs were consistent with those of other carers of people with dementia described in previous research. For example, a study by Milligan, Roberts and Mort (2011) found that even routinely used technologies become of little assistance to people with dementia as cognitive and memory impairments become more pronounced. In these cases, it fell to family carers or paid care workers to prompt the person to use the devices. Newton et al (2016) emphasised the key role carers play in ensuring the adoption of technology by the individual with dementia by either purchasing new items or adapting existing equipment to the person's changing needs.

The interviews with people with dementia further highlighted the key role of a carer within the complex social and technological arrangements underpinning technologically supported care practice. While technology is described as a 'mediator' acting between the person and the world to make the world more accessible (Brittain et al, 2010: 274), in the context of care, this role is enhanced by the carer who becomes, in turn, a mediator between the person with dementia and technology. According to Brttain et al (2010), technologies become disabling or disempowering when they are broken or incomplete, and as argued above, designing out the carer from the technologically supported care network results in the abandonment of technologies. An example of technology being perceived as an interference and rejected by a person with dementia who is not supported by family carers to use the equipment can be found in the exchange with MO below:

> *'LO: Going back to the gadgets and technologies, how do you feel about technologies in general? I have noticed that you have a tablet.*
>
> *MO: I know, I've got that. I've got a computer, but I cannot work them.*
>
> *LO: Why not?*
>
> *MO: Well, the computer is my son's and he brought it. And it was different to what mine was and I can't get on it. He said I've fixed it up that it just comes on, but when I want me emails, I can't get on it. Because I've got to sign in and this computer's different, it's got some letters, perhaps m and c on the same button, and I don't know which to press to get the right one. And I haven't got me patience with it, so I can't be bothered… I can't be bothered with it. It just, it just gets me worked up if it doesn't do what I want it to do, I get worked up about it and then I think it's a waste of time. So I switch it off!'* (MO, person with dementia)

As MO had difficulties with using her computer, she was also not able to use a security video camera installed above her front door and linked to the computer. This resulted in her abandoning the video technology and relying on her own eyesight and the front door's glass window to determine whether the visitor at the door should be allowed to enter her house. MO explained that she would have been happy to use the computer with some help and was willing to learn on 'a one-to-one' basis, however her daughter who was her primary carer was not able to support her with this:

> *'MO: I mean especially for somebody like me, I need a one-to-one. Well my daughter's no good, she won't do it at all, she is worse than me. She is worse than me, she does not want to do it… She [daughter] doesn't have anything to do with computers.* (MO, person with dementia)

MO's experiences of using some technologies and abandoning others illustrates the necessity of approaching care technologies as a part of multiple social arrangements involving people living with dementia, their carers, neighbours, health professionals and technology developers. According to Peine et al (2015), when technological design collides with everyday lives of older people, the existing established relationship within the network of technological objects and human relationships is altered. In MO’s case, the new technologies placed in her home by her family members threatened the existing routines and her pre-established relationship with other material objects within her home. Without any support with embedding these new technologies into the materiality of her home, MO was unable to use them.

7.3. Technologically mediated ageing in place

To understand the role of technologies in care further, this section will focus on narratives describing the actual use of technologies within the home offered in the course of the interviews with people with dementia and family carers.

Nearly all respondents with dementia who took part in the current study reported using household technologies on a day-to-day basis. For instance, JB who was diagnosed with Alzheimer’s disease and had mild memory problems at the time of the interview described his routine use of microwave as follows:

> *‘LO: Do you use the microwave?*
>
> *JB: Oh yes, that’s what I use mostly… R [wife] does a lot of it the main food, you know, but every so often I have to cook little bits. All I do also most of the time is heat something up, you know, if I’ve got a meal or something like that, it’s already done. Let’s have a look here [opens the fridge and goes through things. Takes out a plastic food container]. Here look, these are OK if I defrost it, cos they came out of the freezer, yeah.*
>
> *LO: So you don’t mind using the microwave?*
>
> *JB: Oh no no, that’s alright. It don’t [sic] mind me, so that’s why I use it, if it did I wouldn’t dare do [laughs].’* (JB, person with dementia)

Although JB could no longer cook hot meals from scratch, he used the microwave to warm the meals his wife cooked for him. JB adapted to the memory changes and the limitations these caused by using this household technology item to enable self-care. This also meant that his wife, who was his primary carer, could continue visiting her friends and maintain her social networks.

For JK, a man in his early 90s living alone, history and sports programmes he watched on television were the source of intellectual stimulation and provided topics for conversations with his acquaintances during grocery shopping trips:

> *'I'm here by myself, I don't go out regular. I do go out but I get some pleasure out of going out and doing these things. I don't want to be totally isolated. And although you're not going to be totally isolated, you got your telephone and things like that, but I like to get out and meet people and have a conversation with them, and discuss things that you've watched on TV and what have you, and football and cricket, and all the rest of it.'* (JK, person with dementia)

JK did not have a mobile phone and reported that he had no interest in acquiring one as he felt that the landline was sufficient for keeping in touch with geographically distant family members. JK's routines and practices of self-care developed over a number of years spent living alone in his spacious two-storied house. The everyday technology items – the TV set, the cooker which JK used to make hot meals for himself, and the landline were all a part of the network of material arrangements enabling JK to age comfortably in his home. These were intertwined with well-established social arrangements that have emerged over a number of years. JK's next door neighbour brought him a fresh newspaper every afternoon, and the neighbour living across the road knocked on JK's door every time she went grocery shopping to ask whether he needed anything. JK also used the Companions service provided by the case partner organisation for trips to local cafes, cinemas, places of interest and supermarkets. JK described his day-to-day routine supported and enabled by well-established social arrangements as follows:

> *'I've got a good neighbour there, I've got a really splendid neighbour here who called to see me this morning and asked me if there's anything I required. Well I've got my system and I stick to it, it's shopping on the Friday. And I get all done, and I thought, well I will be going out this week with our friend, the lady that drives, I'll have that organised another way. No I keep in touch, well I ring a couple of chaps*

> *that I served me time with. And we share each other's conversations, football, rugby and things like that.'* (JK, person with dementia)

This smoothly running system entailing simple technologies, such as a landline telephone, as well as social arrangements with neighbours and locally available services made it possible for JK to live alone at home and to enjoy what has been described by scholars of technologically supported care as 'an autonomous yet ageing life' (Gomez, 2015: 99). JK's identity – that of an independent, self-sufficient person – was not compromised in the process of him carefully balancing these socio-material arrangements. Rather, they enabled JK to maintain his physical and mental wellbeing, or as he put it himself, to keep himself 'occupied mentally and physically'.

When interview discussions with JB and JK moved to exploring the use of existing technologies that the respondents already had in their homes and potentially acquiring new items, both men expressed reluctance to engage with 'new' care technologies. In JB's case, the falls pendant that was a part of a telecare package installed in the house he shared with his wife was put away by him and never worn, even though his wife insisted on him using it, as the exchange below demonstrates:

> *'LO: when we spoke earlier, you said you've got a pendant, is it a falls pendant with a button linked to the Careline?*
>
> *JB [addressing his wife, RB]: You know, R? I don't really wear it, she might wear it. Do you wear the Careline pendant?*
>
> *RB: Yes.*
>
> *LO: And you also have one and you don't wear it, why not?*
>
> *RB: Yours is hanging up there [points to the back if a chair] but there's no pendant on it. What have you done with your umm [pendant]? We originally had one on our wrists, what have you done with yours?*
>
> *JB: Oh I don't know, it's around somewhere.'* (JB, person with dementia and RB, carer)

When asked by the interviewer about the reasons for not wearing the pendant, JB indicated that he did not feel the need to wear it:

> *'LO to JB: And why don't you wear yours?*
>
> *JB: Oh I don't see, I can't be bothered with it really.*
>
> *RB: He's perfect, he's not going to fall over [everyone laughs].*
>
> *JB: Well If I do fall over I'll get up again.'* (JB, person with dementia and RB, carer)

JB's comments draw out two issues with acceptance of technologies by older adults – 'perceived need' and concerns about care technologies contributing to the breakdown of fragile socio-material arrangements that support autonomy and help to maintain independence (Peine et al, 2015; Gomez, 2015). In the part of the interview with JB about living independently at home, discussed in chapter Six, he described his daily routines and activities that he felt constituted 'independent living'. These included being able to drive to the beach to walk his dog, driving his wife to the nearest town where she could go shopping, and taking care of the garden when the weather permits. Wearing the pendant would not have provided any apparent immediate benefits in completing and enjoying these tasks – something which Czaja et al (2013: 38) describe as a 'perceived personal need'. That is, whilst it was recognised that there may be some benefits of this technology for other people, JB himself did not feel a strong personal need for it - a theme also noted amongst the focus group participants of Lorenzen-Huber et al. (2011). An important observation from this thesis is that whilst previous research has referred to the potentially fragile nature of technological arrangements (Gomez, 2015), it should also be noted that these can disturb fragile social relations. In JB's case the social relations that he continuously referred to throughout the interview were with his son and daughters living nearby. In his explanations of why he did not need to use the falls monitoring technology, JB indicated that he could rely on his children to 'pop in' to check on him and his wife, rather than alerting a call centre through the pendant in case of a fall. JB's concern was that technology might become a substitute for, or serve to reduce, the number of visits from family members. Whilst the previous literature has noted some of the productive socio-technological assemblages that may emerge when older people engage with technology, it should also be noted that they may serve to disrupt potential valuable pre-existing ones. Not only could such technologies lead to social isolation and loneliness (see Milligan et al, 2011), but they might also disrupt long-established routines and connections which hold value for those with dementia.

In addition to replacing some of the roles that important social contacts (especially family members) filled, the interviews also showed evidence of what might be called the secondary work of adopting technologies. This work included installing the technologies, completing basic maintenance tasks, such as replacing old batteries in sensors, creating a digital account to complete a set-up process for a door monitoring system, and even at times activating an alert on a pendant worn by the person with dementia:

> *'I press his [husband's with dementia] own buzzer, he wouldn't know how to press it, but I can operate it while it's on his hand for help.'* (CA, carer for spouse)

> *'LO: Do you use the internet for anything? Do you go on a computer?*
>
> *PS: No, I used to.*
>
> *LO [pointing to a laptop]: There's a laptop there.*
>
> *PS: I can't. The boys [sons] when they come up use it and do all the things, payments and the cancelling, and things like that. They just do it in a minute.'* (PS, person with dementia)

Furthermore, carers reported performing other additional tasks that emerged as a result of installing technologies in the homes of their family members with dementia, such as placing or moving a piece of equipment out of reach of the person to prevent them from dismantling and disassembling it:

> *'Any of the technologies that we look at or want to engage with, they've got to be inconspicuous. So we moved these sensors out of reach, they are quite high up on the wall near the ceilings that mummy is not really looking up there, and if she does she is not tempted cos she can't reach it, so it's one of those things. If it's*

> *conspicuous it will get pulled apart and dissected out of curiosity.* (WJ, carer for parent)

What these quotes show is that whilst care technologies might reduce the need to rely on carers of family, they might also bring a further reliance on them in terms of maintaining and operating this technology. In addition to the installation of these technologies, which often included the need to install the internet for the first time, there was a need to maintain them and at times to operate them on behalf of the person with dementia. This secondary work often fell to carers and brought another layer of reliance by those with dementia and a potential increased feeling of helplessness (Mort et al, 2013)

Lying more deeply than this discussion of perceived personal need, was the extent to which technology may serve to mark out, label or (re)position respondents. For example, some of the carers pointed out in the interviews that they were wary of acquiring assistive technology items that they felt could mark out their family member with dementia as needing assistance, as WJ explained below:

> *'As mummy is wondering more and more, so if she ever got out of the building and wondered off, she did once and police had to be involved looking for her, and that's what generated us looking for technology specifically… We would have utilised it [the tracker], even until now even more so, if it was more inconspicuous, so if it was like a watch or something she puts on her hand, something like a pendant going round her neck that she doesn't really think about.'* (WJ, carer for a parent)

Whilst there is a large geographical and sociological literature which has talked about the role of clothes and accessories as markers of identity (Boultwood and Jerrard, 2000; Croghan et al, 2006; Schofield and Scmidt, 2005), the findings from my research show that a similar observation can be made for technology. Although there are potential safety and health benefits of such technological accessories they can be seen as part of identity expression in the same was as clothes (see Crane, 2012) – but rather than being something that is positive and demonstrating their autonomy of expression, they are markers of difference which position them, in their opinion, negatively.

The potential of technology to disturb these micro-geographical arrangements has, in previous literature, also been applied to the discussion of the materiality of the homespace (Milligan et al, 2011; Lupton, 2014). These studies note, for example, a resistance to technology based on its potential to disturb more mundane and sunken-in arrangements (Langstrup, 2013) and disrupt the arrangement of the homespace and lead to a level of medicalisation of the homespace. The interviews added nuance to this discussion:

> *'JK: Saying this, handles on the bathroom, things like that, well they've come down to see what I want and they've done the job. Handrails at the back stepping down into the back garden – the job was done. I've had no problems that way.*
>
> *LO: And those handrails, are they helpful?*
>
> *JK: Oh golly aye! Yes!'* (JK, person with dementia)

> *'SM: I've got a shower, I had a bath. And now I've got an adaptation in the bathroom, I just walk in and then there's the shower, electric. You pull the cord and you get that water from the shower.*
>
> *LO: What do you think about these adaptation?*
>
> *SM: Yes, it's very good yeah.'* (SM, person with dementia)

Such responses highlighted that those with dementia classified technologies in different ways, with some seen as more acceptable and less intrusive than others. Simple technologies like handrails, for example, rather than disturbing routines served to keep them in place. For example, being able to get out of a chair, use the bath and enjoy the garden were all seen as benefits of this technology. For the wider literature, this observation is important in noting that certain technologies may have what can be termed as 'permissible intrusiveness' – that is, they were visible to others, but this was outweighed by their role in assisting independent living and meaningful routines. As Peine et al (2015) have noted, there is potential for older persons to be seen as agents that create and develop meaning for later life through their interactions with technology.

Such ‘permissible’ technologies, the interviews suggested, quickly become normalised within the material space of the home, as the exchange below demonstrates. The conversation is from a dyad interview – with JB, a person with dementia, and his wife RB, who is his primary carer. RB has significant mobility problems and has had both her hips replaced:

> *‘RB: We’ve got a few Careline bits about, you know, fire alarms and umm… Some of the things are for me as well cos I’m having a hip problem so the grabbers that they put on the shower and things like that, they are for my benefit really. And that rail.*
>
> *JB: Oh yeah, rail going down the steps too, we put in the garden down there and also the rail in the front there, it was for R.*
>
> *RB: That was for my benefit and obviously you later on might want it, you know…*
>
> *JB: Yes, yes, they’ve done it well, didn’t they? It’s only just been done.*
>
> *LO: And has it made things easier for you?*
>
> *RB: Oh god yeah, yeah.*
>
> *JB: Well it’s like in the toilet too, we’ve got a few rails for us.*
>
> *LO: And have these adaptions changed the feel of the house in any way?*
>
> *RB: Well yeah, because it’s helped me with all these. But we haven’t had much, nothing really done in the house.’* (JB, person with dementia and RB, carer)

What is significant here, is that these technologies are used to aid pre-existing routines, rather than creating new ones. So using hand rails, raised toilet seats, walk-in showers were a smaller part of a wider routine and hence were quite acceptable, newer technologies such as digital video cameras, laptop computers and tablets created new routines and (re)shaped the material space of the home and hence were more likely to be rejected (see Lorenz et al, 2019).

The interviews revealed that technology has a wider knock-on effect on the material arrangements and spatialities of care. For example, WJ and WL who cared for their mother with dementia had a new digital monitoring system installed in the mother's apartment. The sisters lived some distance from the mother's dwelling and took turns to visit her during the day and in the evening. The newly installed system sent an automatic alert to their phones whenever a movement in their mother's flat was detected. Below, is WJ's description of the system itself:

> *'WJ: We used to have also [system] installed, and that was, so it was called [system]. And it was sensors around the property, and it would sense where movement, it would detect movement so we knew where mummy was in the property, how long she's been sitting, you know, sedentary and has she gone to the bathroom, and et cetera. So we'd be able to map throughout the day, just given a view of what she's been doing during the day.'* (WJ, carer for parent)

According to WJ, the system was installed as a response to the mother's changing needs and in particular to prevent her from getting lost as a result of leaving her flat and walking away from the building:

> *'WJ: It was in response to mummy's umm changes in her condition. She has Alzheimer's, a form of dementia, and it was the changes in her condition that led to us to want and to look for new things, different products and services to support her need. The sensors I spoke of, the alarms that she if does leave out the door, it triggers the alarm and we can be there within 5 minutes so it limits how far she's gone. So just all those things we've done to as a response to her changing her habits and what she does because of her condition worsening.'* (WJ, carer for parent)

WJ then moves on to describe the new care patterns and practices that emerged as a result of the system installation. Both her sister and WJ's routines were altered significantly, as the information about their mother's movements during the night began to come in through to their mobile phones:

> *WJ: 'Yes, what happens is when we receive and alert, we just drop what we're doing and just run over here. That's it, there's nothing else. We just drop what we're*

> *doing and come straight here… So the number of visits are more now… It just means now we can react informed, we're informed so we can react. So in terms of that relationship it means we are here more often, definitely the amount that I spend physically with mummy is much more now than it used to be, much more. In fact my mother is only on her own for the entire day probably for about 3 hours on her own, that's it.'* (WJ, carer for parent)

Whilst this technology arguably shortened the distance between the carer and the person with dementia, so too it changed the pattern of care. At one level, such technologies allowed family members, in particular, who were not geographically proximate to still consider themselves as 'carers'. Having access to telecare systems, such as the one described by WJ, allowed them to 'care-at-a-distance' and, as such, allowed them to be alerted to things such as falls (and hence provide care) (Pols, 2012; Aceros et al, 2015). Moreover, the interview with family carers noted that it also served the important function of allowing them to overcome the guilt of not providing care (discussed in chapter Six) even if their care practices only extended as far as having the technology in their homes. Whilst previously WJ's mother's daytime routine would be capped with a final visit in the evening, the alarm has meant that night movements that the family carers would previously have been unaware of became something that needed to be attended to. Eventually, WJ reported, the family had to abandon the system in part due to it malfunctioning and sending false alarms to the carers, and partially because the high number of visits became impossible to sustain. This affected the carers' wellbeing and they made the decision to remove the equipment. The wider contribution to the literature here is that whilst such technology can be seen as increasing the level and depth of care, they may inadvertently bring unnecessary levels of care and visitation and eventually lead to a strain on relationships and a disengagement with the technologies.

The interview discussions also highlighted that the presence of technology served to reshape, for some, the definitions of care. This was seen most overtly in the interview with JST, a warden at a semi-independent housing scheme – whose duties, in addition to keeping the building safe and comfortable for the residents and visitors, included organising and assisting technology installation in the residents' flats and completing routine maintenance tasks.

> *'JST: I can see other things, it [the new telecare system installed within the building] comes with a tablet and the tablet allows me to, you know, when people tell me that they're going away I can put it on the tablet. There's a system of fail safes on all telecare systems, we have the PIR [passive infrared sensors] connected to the telecare system and if somebody doesn't move between a set time, in our case 6 o'clock till 10 o'clock, I will get a report of an inactivity, you know. My system allows me to if I know somebody has gone on holiday I can stop the inactivities coming in and false alarms coming through to meself [sic] or through to the main telecare provider.'* (JST, professional)

While JST was happy to explain in detail the functioning of the new telecare system and his interactions with the technologies at his disposal, his responses about supporting the residents living in the scheme indicated that he did not feel that care provision was among his duties:

> *'LO: What is your involvement, how do you support the tenants?*
>
> *JST: Specifically about people with dementia?*
>
> *LO: Yes*
>
> *JST: This is independent living, you know it's not care. Care can be provided but, you know, I'd just like to make a point that it isn't independent living. My function is additional support for tenants who are living independently but mainly to signpost and liaise with the tenants here and their families and support services…My role is more of an intensive housing function, it's not what I'd term care, but anybody again one of the safety nets, if I feel as though somebody's struggling to live an independent life with us, I can contact social services and ask for an assessment, or I can contact the families to express concerns. If the family are not taking any notice and I'm still concerned, I can put a safeguarding referral into social services.* (JST, professional)

So whilst JST performed safeguarding duties as well as checked on the tenants every morning by calling their flats or by visiting them in person if there was no answer to ensure that were safe, had not fallen and even whether they had eaten, he was adamant that he was not providing ‘care’ (Milligan and Wiles, 2010; Roberst and Mort, 2009). Whilst at one level, JST’s response echoes some of the literature which talks about masculinity and care (Baker et al, 2010; Robinson et al, 2014) it was the technology which appeared to be a distinguishing characteristic in how he framed his contribution as not being ‘care’. Rather than proving care *per se*, JST saw his primary role as installing and maintaining technology – and this technology provided him with a discursive device through which to distance himself from the label of carer. Important for the wider discussion of dementia and technology, such observations illustrate both how technology may bring in new care-related roles – such as JST’s mentioned above or the call centre operators such as those observed by Milligan, Roberts and Mort (2011)- it might also lead to a stretching of what is meant by care.

It was also revealed that the materiality of technology also served to reshape the material arrangement of the home and the practices therein. Certain devices – such as passive infrared sensors and, in some cases, landline telephones – required a particular locating in the home. This in turn led to a rearrangement of the homespace and hence an interruption to the material familiarity when those with dementia needed it most (see for example Peine and Herrmann, 2012). More significantly, this placing was often not something those with dementia had a clear say in, with practical considerations such as the distance from a [phone point or wi-fi connection] meaning that tech providers or carers were the ones who often rearranged the homespace to accommodate this technology. In this context, technology not only required a change to everyday practices and navigation through the homespace, it also the double effect of reducing the sense of ownership of this space that those with dementia felt (see similar arguments by Milligan 2000; Wiles 2003; Angus et al, 2005). Whilst the literature on ageing has referred to the importance of maintaining familiarity in the homespace as people age, and the specific practices that individuals might undertake to do this – such as the positioning of particularly important possessions, or a ‘miniaturisation’ of their living space (see Rowles et al, 2003) - such examples from the interviews revealed that such processes of ageing were less available to those adopting dementia care technologies. Whilst Langstrup (2013: 1017) has spoken about the potential ‘unruliness of the home’ exacerbating illness and being potentially dangerous, the interviews also suggest that technology may contribute to this unruliness in disturbing familiar material arrangement and navigation through the homespace.

A further potential barrier in the acceptance of technology was its ability to over-promise in the eyes of those with dementia. For instance, KS, who wears a fall detector designed as a bracelet had a limited understanding of where the bracelet can and should be used. Usually, such technologies do function in a shower as their purpose is to alert a call centre in case of a fall. At the same time, their range is limited to the space within the house:

> *‘LO: Does it work in the shower or do you have to take it off?*
>
> *KS: I take it off, I take it off. I don’t know whether it works, should work or not but I take it off to be on the safe side.*
>
> *LO: OK, so do you think it works well for you?*
>
> *KS: Yes, yes. This is why I’d like something for outside, to give me more confidence to go out.’* (KS, person with dementia)

Whilst KS could be categorised as an ‘adopter’ of the technology there was potential for her to stop using it on two fronts. On the one hand, the technology was seen as deficient in that its range was limited – something that she only found out after a fall outside. Second, and interrelated, this failure meant that it was not able to be integrated into her pre-existing routine of walking her dog outside and was thus unable to become normalised and unobtrusive within her home and immediate environment (Robert et al, 2010; Neven, 2010)

7.4. Gatekeepers and advocates – those who help technology (non)adoption

In this section, I will examine the perspectives of those research participants who were involved in the design, development, commissioning and implementation of technologies for care, constituting a network of actors connected to one another and to the participants with dementia and carers through the case study organisation's dementia befriending scheme. This group was varied and included digital application developers running their own technology start-ups located in the area of the city known for hosting innovative businesses, commissioners and professional stakeholders from local health and statutory bodies, and volunteer befrienders who visited people with dementia in their homes. The interviews revealed that the respondents' respective positions within the technology networks were often overlapping and sometimes conflicting.

As discussed in section 7.2., technology developers expressed a consensus in their perspectives on technologisation of care, with some pointing to the inevitability of technology replacing human workers in all areas of human activity. For instance, TD, a successful developer running his own technology studio described his ideas as follows:

> *'[…] Is it a legitimate fear that technology is going to replace their [people's] jobs? Yes, one hundred per cent. And that's the reality of whatever they do or whatever I do, I think. We haven't seen, we're not even at the tip of the iceberg yet with artificial intelligence becoming more of a thing and ubiquitous connectivity. We're now at the start of this technological revolution so, absolutely. I think it's happening.'* (TD, technology developer)

In this context, the technology developers interviewed for this research felt it was important to reach segments of the market seen as yet untapped – older people and those living with dementia. Among the developers' priorities was the design and production of viable marketable products for social care targeted at older people that commissioners of health and care services would be willing to approve and acquire in large quantities. This desired collaboration, however, was not easily achievable by the developers. Although many technology companies were keen to sell their newly developed products quickly to the NHS and social care commissioning bodies, the latter often did not share this urgency, as user and/or patient safety and an efficient use of public resources were the organisations' primary concerns. Below are quotes from technology developers evidencing their difficult relationships with the NHS and social care commissioners:

> *‘TD: The barriers to work with the NHS and social care partners is, I guess, the speed at which they make a decision, and the speed at which a decision can turn into work, which can turn into getting paid essentially. […] A lot of them [people working for the NHS] would not understand the reality of running a business. […] So eventually your job gets signed off, you go to a sort of finance department and you can, I’ve waited up to 6 months to get paid and that was on the [tech partnership] Project, which was probably the longest. It’s the sort of work you want to do but you can’t, you couldn’t just have all that work because it’d be difficult to grow a company. There’d come a point where you just wouldn’t be able to pay people’s wages.’* (TD, technology developer)
>
> *‘ZM: Right, so you can develop a product but getting it commissioned is tricky.*
>
> *LO: By the NHS or social care?*
>
> *ZM: By NHS and social care both. You know, both councils and NHS organisations are very reluctant to buy a product that isn’t already being used by another council or NHS organisation. And it’s very difficult to get round that.’* (ZM, technology developer)

In order to overcome some of the barriers and to demonstrate that concepts for newly developed care technologies would meet a previously unmet need of older people or people living with dementia, the developers sought to engage with potential end users through ‘co-creation’ activities (Wherton et al, 2015). It was found that engagement of this type became a necessity for all technology developing companies who took part in this research. The interviews with developers also revealed that they varied in the ways that they understood and engaged with the co-creation process. These ranged from those who paid little attention to co-creation as a concept through to those who made more concerted and meaningful efforts at the process. The interviews were useful in unlayering the extent to which tech developers engaged in co-creation. Although all, ostensibly at least, reported that they undertook co-creation in developing their technology, the ensuing interviews often revealed that such engagement was often superficial:

> *‘ […] Some of our more enthusiastic technology chaps know that user need exists and they all fill out their business model canvases where they talk about their unique selling points and what customers might want. And they talk about lean start-up methodology which is designed to extract user need. I sometimes worry that for them it’s not something they’re taking seriously as they should. And I sometimes worry if I do the same thing.* (ZM, technology developer)

The interviews revealed that for many tech-developers there was a blurring of the boundary between user need and commercial success and viability of the product. For them, their first point of reference was to how many units they thought it might be possible to sell and a more general ‘market’, rather than thinking about specific individuals. In other examples where co-creation was referred to in interviews, there was a level of cynicism:

> *‘I think co-creation is a term and it is a buzzword, and if you just go ‘Right, I’ve done some co-creation’ and you didn’t mean it, then it’s just as bad as anything else.’* (ZM, technology developer)

ZM’s’s reference to co-creation being a ‘buzz word’ here is important, as it recognises that some tech-developers saw it as a marketing opportunity as much they did as a way to develop useful technology. Specifically, NHS commissioners and social care providers were keen that technology was co-created and for the developers they recognised that it was important to use the terminology of ‘co-creation’, even if superficially, in order to make sure that their products sell. It should be noted, however, that several examples were observed in the fieldwork where there was a more detailed engagement with the process:

> *‘I suppose probably that some things may just not be that useful for them [people with dementia]. I suppose the way to get around that is to use things like living labs to try to develop or co-create, co-develop products with individuals as well, I mean obviously locally. So I think using Living Labs to really define what the challenges are that people are facing, and then do your technology development as much as possible on the back of that, I know that it won’t always be possible, but I think actually speaking to individuals and finding out what their real issues are and*

> *working with them. And I think actually the engagement process is beneficial for people as well.* (OL, professional)

For OL, it can be seen that the starting point was less focused on commercial aspects and more general markets, toward seeing co-creation as a meaningful engagement with potential users of technology. This, OL believes, will enable technology developers to better understand the personal needs of older people and tailor new technologies to these needs. Significantly, later in the same interview OL went on to note how the process of co-creation should be thought of as a continuous and evolving process, rather than just a one off:

> *'But it does make sense if you trying to develop products for people to actually ask them what they might want to at least iron out some of the challenges in the products as they get developed, so talking to people seems to make sense.'* (OL, professional)

OL's quotes indicate that a less superficial engagement with co-creation is beneficial to both technology developers and users. This type of engagement moves beyond just using co-creation as a buzzword to sell the products - toward one which recognises the market potential in products that have been refined through the process of engaging with older people who will become potential users. This engagement, however, was one that was akin to more classic market research - where someone is given the product and asked whether or not they liked it. Other technology companies showed that they had developed a more refined understanding of the benefits of co-creation:

> *'You have to show them [people with dementia taking part in co-creation sessions] options. You can't sit back and say 'Well, what to do you think?' with an open-ended question. It's far easier to say 'Right, these are the three options of the user interface, tell us which ones you like and which ones you dislike', and then you blend them together. You can't just go 'Right, OK, here's a white piece of paper, what do you think the user interface should be like?' It was very hands-on.'* (SG, digital reminiscence app developer)

> *‘I guess co-creation or sort of bottom-up or whatever you want to call it, for me it’s just faster to do it that way. So you could sit in your little lab iterating for 10 years to hope to get to what the people want or you could just ask them.’* (TD, technology developer)

SG’s and TD’s examples show a more nuanced approach to co-creation - where they challenge the assumptions, seen in the examples noted above, that users would already be proficient with basic technology use. Moreover, their approaches were less of one that demanded opinion on a fully-formed product, but more interested in giving a product which was open to moulding within the process. Such an observation has a threefold importance. First, it facilitated the development of technology which was much more user friendly and tailored to the individual. Second, it is arguably a less hierarchical approach to expertise - whereby the tech-developers believe that they have the correct technologies and the involvements of uses is just one that rates their respective popularity. Thirdly, and cutting across the previous two, TD intimates that there is an economic benefit to this co-creation. Here, his focus was not on the value to the end-user per se, but how a more ‘bottom up’ approach might allow them to get the product through the development phase, and thus to market, more quickly.

Scholars of gerontechnology (for example se Peine et al, 2014) who have explored the impact of technology on lives of older people, have long argued that technology design for older users is often conceptualised through the application of biomedical approaches aimed at fixing the problems and limitations of later life though technological interventions. Peine, Rollwagen and Neven (2014: 204) have introduced a concept of a ‘paternalistic stance’ – a combination of design practices characterised by positioning older people as lacking in capacity to determine which technologies they would like to engage with in their environment and following what is offered to them by designers. The approach thus casts the designer as a figure of authority mandated with identifying and meeting the needs of older technology users. My research has found that the paternalistic approach shapes not only the design of technologies for care but also their implementation - that is - the way these technologies are introduced to older people. The evidence for this came from an ethnographic observation that I carried out with a group of older people some of whom had early stage of dementia. The older people from African and Caribbean backgrounds gathered together once a week at a luncheon club where they had a chance to socialise and eat a traditionally cooked hot meal. A technology company partnered with a local arts charity attended one of the club meetings and distributed ‘Get Fit’ trackers to the members with the purpose to ‘improve their physical wellbeing’ by encouraging them to undertake physical exercise such as walking, monitored by the gadgets.

> *‘When observing one of the members – a woman who uses two walking sticks, I realised that she had not been given the gadget. When TR [company worker] and JW [group facilitator] discussed who was to get trackers, JW pointed at the woman and asked TR if the woman should get the gadget. TR shook her head saying ‘No, she isn’t really active’. After the devices were given out, the three men who had been given the gadgets (C, R and P) strolled around the room, proudly showing the slick black gadgets to those around. The woman with the walking sticks sat in her chair looking around, looking at C’s’ wrist, not saying a word. It was as though she had accepted that because of her mobility difficulties she was not to have the gadget. The devices were given to 5 individuals with higher activity levels, one of them a keen walker.’* (Excerpt from a field diary, 29/11/2016)

The observation revealed the ways in which technology providers discursively positioned people with dementia and their needs – and some of the challenges that arise from this – manly, the decontextualisation of pre-existing technologies and then applying them to the case of dementia. Whilst the trackers have been developed in the context of ‘healthy living’ through physical activity (Rooksby et al, 2014), the attempt to simply transpose them to people living with dementia revealed a lack of understanding of their specific contexts. So, for example, many of those offered the trackers had mobility issues which made the activity trackers either inappropriate of exacerbating their concern about this mobility, and also positioning them as ‘unhealthy’. Running alongside this, the trackers also came with the assumption that people would have email addresses and suitable pairing technologies. Many reported not having the requisite email addresses which meant for some that they were not allowed to have the technology – creating an automatic division within the group. For others, they were asked to provide the email address of a relative. This practice had a twofold impact. First, it inadvertently increased the sense of ‘surveillance’ experience by those living with dementia as their relative with the email address was sent updates on their movements and, second, the organisation was given the data through which people with dementia were watched and could be compared in terms of their activity. Whilst this was presented a light-hearted issue – with one member of staff saying ‘you’d better not skive as we will be watching you’ – the connotations were potentially much more negative (Kontos and Martin, 2013; Kenner, 2008).

The next important group within the care technology network, were commissioners. These played an important role in deciding what technologies would be commissioned and made available to people living with dementia. The interviews and analysis found that these were important mediators between developers and end users - either acting as a bridge or barrier to the final use of technology. An interview with RL, a member of staff at an organisation tasked with setting up internet access hubs for older people across the city, showed that their concerns around the use of these technologies related not to the quality of the product in itself, but how suitable it was for the people who developers wished to target it at:

> *‘So it’s more about those of us who provide public services, the health providers and so on, who have to keep in mind as they commission these all singing all dancing wonderful kind of, you know, you press the button and you send your blood pressure to your doctor, though for some people they wouldn’t know how to switch on the machine to send a reading of their blood pressure. Therefore providing them with very expensive tech isn’t necessarily going to resolve the issues if they haven’t got those basic skills. So it’s about the link between those who are commissioning the tech, who are they really doing it for and how can they ensure that that’s actually serving those who need it most, not to those who are already most advantaged and most able to do things for themselves.’* (RL, professional)

> *‘So the barriers - a lot of it is about seeing the need to be online, but obviously there are also barriers in terms of actual cost as in having access to the internet and also the skills of course as well, which go together really.’* (RL, professional)

The professional identified two issues with the current tech development-to-end user flow: those of cost and those of skill. In particular, RL makes reference to what might be referred to as a ‘technology divide’. Whilst the previous literature on care technologies has referred to the technology divide being heavily associated with access to online technology, especially for those living in rural areas without access to broadband internet (Warren, 2007), she refers to a divide that is more focused on a socio-economic divide, where the cost becomes prohibitive to many. This, in turn, has a knock-on effect in that many of those at whom the technology is aimed do not have many of the basic technological skills which would allow them to operate the technology, even if the cost was not prohibitive. For our wider understanding of the implementation of care technologies at scale, the current research suggests that commissioners can act as filter in gauging the appropriateness of technology (Mort et al, 2013). The earlier sections suggested that for some technology developers there was a tendency to de-personalise and decontextualise care technologies and even, where co-creation was employed, this was often superficial or targeted at speeding up the development and sale of technology. The commissioners, however, were significant in re-conextualising technology. That is, they were able to offer insight into the social and material realities into which the technologies may be introduced and to forewarn of the potential barriers to adoption and limitations of the technology in its current form.

Once the technology had been developed and approved by commissioners, new various actors – including carers, volunteer befriends and members of staff at the case study care provider organisation – played a significant role in whether or not a person living with dementia gained access and had an opportunity to adopt this technology, with the interviews showing that they became important gatekeepers. This group were important in the specific micro-geographical contexts where technology was utilised or abandoned. Within the sample, there was evidence of these gatekeepers both advocating and inhibiting the use of technology. At its simplest, for some this involved blocking access to technology – both advertently and inadvertently:

> *‘When I did the [befriender] training the guy [member of staff] was really good, he showed us loads of different things. He gave us loads of websites, all that kind of thing. I’ve got them all written down, but yeah I think V [person with dementia] literally did just want to talk and watch Casablanca. But I think maybe someone a bit younger, it would definitely be beneficial. […] Well she was 87 so I think she is not probably like a standard tech user. There are obviously going to be people who are using computers and mobile phones and what not in their 80s but it’s not obviously as common as say, you know, someone in their 40s or whatever.’* (SG, befriender)

In much the same way that tech-developers inscribed the users and made assumptions about their practices, so did the befrienders. For SG, this related to the age and the stage of dementia of her befriendee F, and her perception of F’s ability to absorb information and engage with technology. It could be argued that SG’s inadvertent ‘blocking’ of technology use was based on her judgement that was less about the usefulness of the technology and focused more on the limitations of the person living with dementia.

> *‘Probably just the understanding of it [technology], and I think a lot of them [older people with dementia], they’ve sort of been brought up with the mentality that they don’t need technology and I think, no, it’s just a new thing and it’s for young people. But yeah, I think I’d always, I will always use technology [for myself]. I think it’s just built into this generation now that we’re always going to have technology and it’ll probably always expand and get better.’* (SC, befriender)

For SC, the value judgement was a more generalised one. Here, the befriender made an assumption not bespoke to the individual person she were referring to, but a more general classification/stereotype of that age of people not being proficient with or not interested in technology. Other befrienders and members of staff at the befriending scheme expressed similar opinions, focusing on age as a determining factor in people's attitude to technologies. Thus, the gatekeepers were inscribing the older user with their own judgements of what is or is not beneficial to their 'generation', or what might be of interest to the person with dementia, which resulted in technologies not being introduced to the befriendees and ultimately 'blocked':

> *'But yeah I think and it's again, it's people understanding it [technology], so I think maybe again the younger generation may adopt whereas the older generation may refuse, you know, 'I'm not really interested in telehealth'. The younger generation may now adopt it more.'* (UJ, Head of Services)

It is notable that at times these user inscriptions were adopted and expressed by the older people with dementia themselves – an evidence of the double stigmatisation – based on the age as well as the condition, which for some resulted in self-withdrawal from using technologies:

> *'I offered her [person with dementia] to get some help on how to use the tablet, or a laptop, or a computer, or something like that but she told me she's too old for that now, yeah she doesn't really want to get into it, she said it stresses her out [laughs].'* (LS, befriender)

Despite the evidence of some of the respondents acting as gatekeepers who blocked the use of technologies by people with dementia, there were strong advocates of technologically supported interactions who actively facilitated technology use. For example, PR a befriender who visited FR, a man with early stage of dementia, described his befriendee's and his wife's approach to reminiscence technology as follows:

> *'I was offered it [tablet with reminiscence software] by [befriending scheme] and I took it to the befriending sessions, and there was a lot of reluctance initially on their part. I think it was just basically the whole, they were of an older generation, didn't*

> *really feel comfortable with technology, wasn't [sic] really sure what the benefits were and just sort of scared them a bit.'* (PR, befriender).

Whilst ascribing the reluctance to engage with technology to generational factors, PR nerveless made the decision to use the technology for reminiscence activities with the befriendee. PR convinced FR to try the technology by drawing on the example of FR's great grandchildren who used iPads regularly and even brought them with them when they visited their great grandfather. PR noticed that his befriendee felt that the great grandchildren's technologies introduced an element of distance into their relationship:

> *'I think before we started using this tablet he [befriendee] would sort of say about how his great grandchildren had iPads and stuff, and how he couldn't get his head around it, and how he felt very sort of distant from them because of it. He felt like there was a barrier and he didn't understand them.'* (PR, befriender)

To remedy this, RP began to use the tablet for reminiscence activities with FR during the befriending visits, which resulted in FR feeling comfortable with tech and more connected to his great grandchildren:

> *'[…] by using this [the tablet] it made him feel more close to his family in a way because he was able to, maybe he was able to appreciate what it was they were getting from the technology they were using because he was sort of benefiting from similar technology himself.'* (PR, befriender)

This gatekeeper ultimately enabled the adoption of the technology and did this through several interweaving techniques (Schulz et al, 2015; Peek et al, 2016). First, PR acted as 'translator of technology' – explaining to the person with dementia how it worked and some of the possible benefits of this. Second, where it was seen that the tech developers de-personalised technology, this gatekeeper 're-personalised' the technology. The reference to the great grandchildren both gave a cognisable context for using the tablet – i.e. it was something that the person with dementia had seen before, albeit in a different context (his great grandchildren playing games on it) – and also used this intergenerational connection to encourage its use. Being able to have a tablet similar to his great grandchildren offered FR a way to engage not only with the technology but also a favourable point of connection with his great grandchildren. This wrapping of technology in familiar and social context was key to the adoption of technology in this case.

Another example of a befriender acting as an advocate of technology was offered by SC, who was a befriender to a number of people with dementia. SC talked about one particular person who lived with later stages of dementia, and who had never used tablet technologies with digital applications previously:

> *'It was quite advanced stage dementia so the person I'm thinking of, there were a few different people but with the person with advanced stage dementia it was very much keeping them company, chatting to them, ensuring that they were OK, and actually we did use technology because I took my iPad and we looked at photographs and then we were able to have a really nice conversation about her past and where she grew up and things like that. And we were able to do that through photographs and things but other people, it was mainly based in the house, I didn't actually take anyone out. But it was reading to them or watching the TV with them, having a conversation with them and things like that, nothing too extravagant.'* (SC, befriender)

This case was a further example of what was referred to earlier as 'translating' technology, but this befriender took it further by appropriating the technology. The iPad was used by the befriender to help with reminiscence work, using it to google old photographs of the city which the person living with dementia could relate to and talk about. For this befriender - person with dementia relationship, technology offered a useful point of connection, and for the wider understanding of care and technology it illustrates how the presence of technology might lead to more organic developments of its use for care. It also illustrates how befrienders may work as introducers and advocates of technology - with this this example showing how introducing the iPad into a happy conversation (where the person with dementia is empowered as being able to remember and offer new knowledge to the befriender), might provide a way for the person with dementia to become familiar with new technology and, perhaps, provide a platform onto which more formal care technologies using the iPad could be layered in the future (Peek et al, 2015).

The study of the perspectives on care technologies expressed by those who use them – people living with dementia and carers, those who commission and develop them, and those who either promote or act as a barrier to its adoption, has revealed a consensus in the views of professionals, people with dementia and family carers relating to the balance between human interaction and technology in care provision: all groups viewed technology as additional to human interaction rather than as an alternative. The theme of care delivered by human carers, paid or unpaid, alongside technological solutions was a salient area that emerged in the course of this research.

This research has also revealed the tensions that exist between the understandings of technologies of care, present in the views expressed by professionals, family carers and people living with dementia. These tensions can be explored through the 'science studies approach to technological artefacts' proposed by Milligan et al (2011: 348). The scholars suggest that technologies themselves are 'social' because they are conceived and produced 'within complex social arrangements' which are translated into practices (Milligan et al., 2011: 348). Furthermore, the practices of care themselves are altered and redefined with the introduction of care technologies (Peine et al, 2015). The vision of newly emerging care practices offered by the professionals in this study is rooted in the policy discourse which conceptualises the older user as an expert in own health and care, responsible for managing long-term health conditions, living independently in own home and using technologies to support daily routines and to connect remotely to health and care services. Although the professionals expressed an understanding of the importance of human contact to older people receiving care, the drive to achieve efficiencies in public spending on social care was given an equal weight. In contrast, carers and people living with dementia emphasised the key role of the human carer within the complex network of care arrangements and technologically supported practices (the notions of the 'hybridity' and 'complexity' of care). Possible implications of the drive to exclude or 'design out' the carer in pursuit of the reductions to public spending cased concern and anxiety both among family carers and people with dementia. Furthermore, technologies were perceived as an interference, a hindrance or even as a danger to life without the mediating support of human carers.

7.5. Concluding remarks

With this chapter, I have offered a contribution to the scholarship on geographies of age and technology studies. In this study, people with dementia predominantly used an array of everyday household technologies which, as I shall argue further in this thesis, sink in their everyday routines and do not disrupt spatial and material arrangements of their homes. The analysis of carers' experiences of assistive technologies has demonstrated that technologies of care are abandoned by cares when they add to the burden of care and disrupt well-established care practices. Further this chapter has illustrated, that the paternalistic approach to technology design and implementation in care is rooted in the biomedical view of older age whereby technological innovations are proposed as a quick fix solution to the problem of ageing.

Chapter Eight: Conclusion

8.1. Introduction

In this thesis, through a qualitative case study approach I have addressed calls from policy makers and academics for research into dementia care in the community involving people living with dementia, family carers and voluntary organisations providing services (Department of Health, 2015; Banerjee, 2010; Keady et al, 2012; Carmody et al, 2015). Despite increased interest in dementia over the last few years, the need for qualitative research into experiences of people with dementia and carers remains (Cardmody et al, 2015). Through interviews with people with dementia and carers I have highlighted the importance everyday assistive technologies and home adaptations play in their lives; indeed, my findings echo Joyce and Loe's (2010) point about science and technology being central to older people's lived experiences. Thus, in my thesis I sought to contribute to the scholarship on experiences of older people with dementia who negotiate their lives using everyday technologies (Brittain et al, 2010). With the expansion of the voluntary sector into the provision of dementia care, the geographical enquiry has focused on exploring the responses to the 'community turn' (Macmillan and Townsend, 2006: 15) of those who receive support from voluntary and community organisations. By bringing the three areas of enquiry together, namely, living with dementia or caring for a family member with dementia, receiving and providing voluntary care, and interacting with everyday and new technologies of care, I endeavoured to understand the new forms of care produced as a result of these inter-relationships. In this final chapter, I summarise the research findings as they address each of the research objectives and discuss conceptual contributions arising from my work. I conclude with outlining potential avenues for future research.

8.2. Research objectives revisited

To address some of the gaps in research outlined above, I aimed to achieve three objectives in this thesis. In fulfilling the first objective - to explore responses of people with dementia, carers and volunteers to the 'community turn' in care - I sought to examine how people living with dementia and their family carers have been affected by the diminishing provision of publicly funded support. I also investigated how the decrease in locally available dementia services has resulted in voluntary organisations attempting to meet the needs of people with dementia and carers, often without having the necessary resources to do so.

The second objective of my study was to explore new understandings of responsibility for care produced through the move to more voluntary and technologically delivered services. Through the examination of accounts of those who commission dementia services, those who deliver them and those who receive them, I discovered conflicting notions of what constitutes care, who should shoulder the responsibility for providing care to those with dementia, and which elements of care should be performed by technologies rather than human carers.

My third objective was to examine the role of voluntary and technologically delivered care in facilitating independent living (or what's been termed 'ageing in place') and to understand particular forms of spatiality produced at the intersection of 'ageing', 'care' and 'technology'. Drawing on the geographical scholarship on place, I explored the understandings of those living with dementia and family carers of the notions of independent living and personal autonomy in older age ('ageing in place'). Using the interdisciplinary lens of Science and Technology studies, I explored the emerging practice of performing care at distance through connecting technology. Finally, I contributed to the ongoing exploration of the role of care technologies in the networks of care.

In fulfilling the three objectives, I hoped to contribute to the currently prescient debates on social care provision in the UK and to inform policy and practice of dementia care.

8.3. Care: whose responsibility?

The views of professionals and social care providers interviewed in this research corroborate earlier British and international studies which indicate that the discourse of active ageing and self-management has been linked to the broader policy agenda to reduce public spending on social care (Wiles, 2003; Milligan and Wiles, 2010; Lloyd et al, 2014). An important finding in this regard was the contrast between professionals' views on responsibility for care and family carers' accounts of their daily lives wholly dedicated to the person they cared for. Overall, while the professionals believed that people in receipt of care and carers over-rely on health and social care services, and called for a greater involvement of families in the process of care for relatives with dementia, family carers' experiences revealed that they neither demanded nor received much support from statutory services. Drawing on the 'healthy ageing' discourse and its constituent parts, such as being skilled in managing own long-term condition, taking responsibility for own health and prevention of illness (Angus and Reeve, 2006), the professionals heralded lifestyle choices as a key factor in staying healthy. However, upon further exploration of the ethos of self-reliance and self-management during the interviews, it was revealed that the professionals struggled to articulate how dementia can be prevented through adherence to a healthy lifestyle. Indeed, recent research suggests that a specific effect of a healthy lifestyle for prevention of dementia is yet to be identified (Haan and Wallace, 2004). This finding further extends the debates on ageism which have outlined new emergent claims and stereotypes about older people, whereby the discourses of burden and dependency have been replaced by the drive towards individualism and self-reliance (Angus and Reeve, 2006).

Shaped by the climate of austerity and cuts to public service provision (Ferguson and Lavalette, 2013), primary concerns of the professionals and commissioners taking part in this study related to achieving cost reductions to local health and care service provision. Whilst this concern was wrapped up in the discourse of citizen empowerment, rights and maintaining independence, the interviewees offered little clarity around these concepts and their translation in living experiences of people requiring services. At the same time, the leaders' calls for people with dementia and carers to become informed, empowered citizens were not supported by any proposals to implement mechanisms through which people in receipt of services could participate in service design and guide service delivery.

This finding contributes to dementia research and practice concerned with the notion of citizenship (Bartlett and O'Connor, 2007). While both have moved from focussing solely on personhood, as theorised by Kitwood (1997), to include the ideas about power relations and inherent rights of people with dementia, there is still little research into how dementia affects exercise of civil, political and social rights and responsibilities (Bartlett and O'Connor, 2007). In relation to dementia care practice, an emerging recommendation to policy makers and practitioners would be to enshrine the concept of participation and inclusion in dementia service design and to provide opportunities for people with dementia and carers to participate and contribute to decision-making panels at strategic levels.

8.4. Broadening the concept of care

Drawing on family carers' accounts of their journeys through the process of caring for a family member with dementia, I have concluded that the concept of care should be broadened to include such aspect as administration or organisation of care, which has not been explicitly understood as doing care, in contrast to personal care, feeding and dressing the person. As discussed in chapter Two, care has been defined by various scholars as 'the provision of practical or emotional support' (Milligan and Wiles, 2010: 737) and 'emotional labour' (Conradson, 2003: 451) practised through interactions with complex networks of actors involved in the care process. My research has evidenced that family carers of people with dementia, particularly those living with later stages of dementia, spend a significant amount of their time on organising care for the person. This is carried out in addition to providing personal care, emotional and intellectual support, thus initiating and completing many formalised tasks, such as care plans, attending to legal issues, making decisions about residential care, medical care, coordinating daily visits from care agencies and so on. These activities do not cease with the transition of the person with dementia into residential care. My research has revealed that family carers continued to support the person with dementia following the person's move into a nursing home, with some cares finding a new role for themselves, engaging in, for instance, care quality checking or coordinating visits from other family members. Thus, this research supports findings of earlier studies into the continued involvement of relatives in care after the person’s transition to a care home (Davis and Nolan, 2006). Broadening the concept of care to reflect these activities will further support the calls from academic researchers and practitioners to make carers of people with dementia visible (Milligan, 2006; Phillips, 2007), and strengthen the case for financial, practical and emotional support for carers (Age UK, 2010). Furthermore, in addition to giving terminological clarity to this discussion, the broadening of the definition could also feed into the discussion of the carer burden and allow more accurate costings of care provision.

8.5. Befriending: between service and friendship

This study has echoed findings of earlier studies as well as contributed new observations (empirical data) to the existing literature around friendship and befriending (Andrews et al, 2003; Bunnell et al, 2012). First, it was noted that from the outset the relationship between the befriender and the befriendee was not perceived by either party as ‘friendship’ because it was bounded and limited by such formal requirements as time limited visits, Disclosure and Barring Service checks, compulsory training for the befrienders and signing of formal service agreements by the befriendees or their carers. However, as new bonds developed between befrienders and people with dementia, some reported that their relationships had elements of ‘real’ friendship. Echoing findings of the study by Andrews et al (2003), my research revealed how both befrienders and befriendees skirted the rules and boundaries set by the befriending scheme and developed relationships outside of the scheme’s remit, participating in social activities, such as birthdays, and continuing to meet and provide support after the scheme closed. Another insight developed through exploring the relationships between befrienders and those living with dementia related to the shift in the position of the befriender, often inadvertent, to that of someone providing care. Whilst they are discursively positioned, at the outset, as ‘providing company’ to the person living with dementia, it has been noted that they often provided personal care, including meal preparation, feeding and cleaning up. This phenomenon of blurred boundaries between befriending, friendship and performing personal care could be further explored through ethnographic approaches.

Second, as noted previously by other researchers, and discussed in chapter Two, interactions with non-family ‘others’ were perceived positively by people living with dementia, and the scheme received positive opinions from the service users (Gardner, 2011; Andrews et al, 2003). The befriendees particularly valued the befrienders’ punctuality and reliability reporting that the volunteers never let them down, while friends often did. This finding may be of use to other voluntary organisations providing services to socially isolated people. Third, the study has further extended the discussion of befriending by adding in the importance of geographical context (see Phillips and Evans, 2018). It has noted the hitherto under-recognised importance of spaces to the befriending process. When the process involved visiting specific places and taking part in activities together, such as watching cricket matches, doing arts and crafts, offering the opportunity to both parties not only to reminisce but to create shared memories together, the bond between them grew stronger.

8.6. Care in the community

This research has found varying degrees of support from neighbours and local community members and organisations available to people with dementia and carers. Echoing findings of research to date, this study has noted that people with dementia and carers drew on support from their established social connections within their communities (Wiles, et al, 2012). Those who felt that their communities were closely knit and supportive reported feeling more secure and attached to the place where they spent their later lives. Whilst policy on ageing with its emphasis on ‘ageing in place’ often focuses on ‘home’, this research has found that other aspects were equally important to people living with dementia. For example, when discussing their choice to stay put in a place, people with dementia recounted what they did outside of the home (visiting local shops, attending church groups, singing in a choir, walking their dogs with other dog walkers and so on), talked about who lived nearby, described the vicinity and its terrain, local transport and doctors’ surgeries. The empirical data also demonstrate that people with dementia and carers living in localities with less established, transient populations, such as student communities, reported feeling less connected to their communities, more isolated and having to rely on family members for help to care for the person to a greater extent. These findings add to the scholarship on ‘ageing in place’ by maintaining the focus on social connections and interactions outside of the home. Although staying in own home is important to some people with dementia, those who took part in this study expressed their sense of attachment to place and connection to the outside world through social and community levels with reference to friendships, local amenities, health care facilities, transport and community groups.

Whilst common reference is made in the care literature to the importance of having family members proximate in order to provide care, the interviews with these family carers have shown the challenges they face and the importance of investigating the dynamics of care provision within families. It was found that there was often an uneven burden of care within families – with those living closest to the person with dementia often expected to take the lead roles in care, and those family members without children expected to provide a greater share of support. Furthermore, pressure was often exerted from distant family members on proximate carers in relation to the quality of care they provided. This research has also found that those carers who reported receiving little support from within their communities and experiencing tensions in their relations with distant family members also talked about being extremely stressed and feeling isolated. Whilst the study has opened up some of the tension existing within extended families caring for a member with dementia, further research is needed which focuses specifically on the dynamics of family relations and moral geographies of care.

8.7. Care technologies

This study has revealed a variety of techniques and tools that people living with dementia used in order to be able to age in their own homes, to maintain established daily routines and to continue enjoying their autonomy. In contrast to the current approaches in research and policy making related to technology and ageing which, according to Peine et al, ‘do not consider material practice and materiality to be an inherent part of later life (2015: 1), this study explicitly focused on the inter-relationships between the material arrangements of home and older people's sense of identity.

Discussing micro-geographies of their homes with my research participants, I noted that they used simple, familiar household objects such as microwave ovens to warm meals prepared by family members or paid carers, post-it notes as medication reminders, recliner chairs as day beds and simple home adaptations to aid their daily routines. I termed these 'sunk in' technologies as they did not appear to disrupt well established material arrangements within the homes of the respondents. In contrast, technology items placed within the home by family members resulted in the disruption of familiar spaces and routines and were abandoned by the people with dementia. It is possible to conclude, that what I termed as 'permissible intrusiveness' of familiar technologies which aided pre-existing routines without reshaping the material arrangements of home enabled a smooth adoption of such technologies by people with dementia.

Exploring the use of newer technologies, I have found that such items as computers, security cameras, falls pendants connected to telecare systems, mobile phones and tablets were viewed less positively by people with dementia. I concluded that unless the person felt that there was a pressing need that could be met by one of these items, the desire to adopt such technologies was less pronounced than in the case with the 'traditional' more simple devices discussed above. Furthermore, subscription fees for telecare and costs for access to the internet were perceived by the many research participants as unnecessary and too high. Another factor that affected technology adoption rates by people with dementia in this study was the lack of accessible information about technology, where to obtain it. People with dementia reported that they were interested in using and learning how to operate digital technologies, such as tablets and laptops if this information was delivered in a way that is supportive of their learning styles and needs. Related to this, I recommend that those commissioning the roll-out of care technologies should take into account the latest research on technology and ageing and be guided by the views of the potential technology users.

Consistent with previous studies (Gomez, 2015; Wiles et al, 2012), I have found that that the home does not always a safe place of refuge for the person with dementia: as the needs change and it becomes more difficult to maintain the dwelling, the person with dementia has to negotiate growing older in place. The empirical data from this study demonstrate that once such negotiations become difficult, a feeling of ‘not being at home’ arises and affective connection to place becomes eroded. Some of the people with dementia who felt they could no longer keep up with the demands of maintaining their homes considered moving to another property. These feelings were mitigated by the installation of the simple ‘low’ technologies and home adaptations, such as handrails, ramps for access, modified showers and bathrooms, and stair lifts. The modifications enabled older people to overcome home ‘usability’ challenges (Coughlin et al, 2007: 1810) thus enabling them to continue living at home and preventing an early transition into residential care.

One of the original contributions of this study to the scholarship on age and technology relates to explicating the under-recognised role of the carer in supporting technologically delivered aspects of care. The successful installation and smooth running of technology products and systems requires a significant input from family carers. Maintenance of technologies requires, in particular digital items, requires learning new skills for some carer and thus adds to the carer burden and already complex care arrangements, particularly for people providing care for those with later stages of dementia.

This research has exposed a contradiction between the purposes behind the introduction of care technologies into dementia care: on the one hand, as noted by Gibson et al (2018: 14), the introduction of assistive technologies is meant to ‘design out’ the carer; on the other hand, as this study has revealed, family carers’ input is vital to technologies’ functioning. Carers are mediators and negotiators of technologies. The enable people with dementia to adapt and use technologies. Another finding of this research is that carers equally can take on a role of a gatekeeper to technologies, preventing their use by the person with dementia, especially if their own lack of skills and confidence serve as barriers to technology adoption. Furthermore, time constrains for carers leave some with very little opportunity to learn and implement technologies, which can be time-consuming. These findings further advance theoretical debates on technologies of care discussed in chapter Two. They support the view presented by Oudshoorn (2011) that rather than being an isolated, off the shelf instrument which can be smoothly introduced into complex networks of care, technology shapes care practices by creating new roles (including family carers) and altering the network itself.

8.8. Future research directions

In addition to the ideas for future research outlined within chapter Eight, future research could address one of the limitations of this study, As noted in chapter Four, one of the limitations of this research was not including research participants with later stages of dementia because of ethical concerns relating to their capacity to consent to take part in this study. While the carers' 'proxy accounts' (Clarke, 2001: 31) collected for this study have provided a partial understanding of technologically supported care - as experienced by the person with dementia-carer dyad - further research with people living with advanced stages of dementia is needed. Future studies employing ethnographic participant observation rather than semi-structured interviews may be useful for eliciting the intersubjective experiences and meanings created by people with dementia through interactions with assistive technologies, volunteer befrienders and family carers (Bond and Corner, 2001; Herbert, 2000). Other research directions could be concerned with implementing a longitudinal approach to the study of people with dementia and carers' interactions with care technologies, as well as following a certain technology item or a system through time.

References

Aceros, J.C., Pols, J. & Domènech, M. (2015) 'Where is grandma? Home telecare, good aging and the domestication of later life', Technological Forecasting and Social Change, vol. 93, pp. 102-111.

Age UK (2010) *Invisible but invaluable.* Available at: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/care--support/rb_oct10_invisible_but_invaluable_report.pdf (Accessed: 2 September 2019)

Age UK (2016) *Living well with dementia (England).* Available at: https://www.ageuk.org.uk/globalassets/age-uk/documents/policy-positions/health-and-wellbeing/ppp_living_well_with_dementia_england_.pdf (Accessed: 9 October 2019)

Ahmadi-Abhari, S., Guzman-Castillo, M., Bandosz, P., Shipley, M.J., Muniz-Terrera, G., Singh-Manoux, A., Kivimäki, M., Steptoe, A., Capewell, S. & O'Flaherty, M. (2017) 'Temporal trend in dementia incidence since 2002 and projections for prevalence in England and Wales to 2040: modelling study', bmj, vol. 358, p. j2856.

Akrich, M. (1992) The De-scription of Technical Objects. In Bijker, W.E. and Law, J. (eds), Shaping technology/building society: Studies in sociotechnical change. Inside Technology series. Cambridge and London: MIT Press, 205-224.

Alderwick, H., Tallack, C., Watt, T. (2019) *What should be done to fix the crisis in social care? Five priorities for government*. The Health Foundation. Available at: https://www.health.org.uk/news-and-comment/blogs/what-should-be-done-to-fix-the-crisis-in-social-care. (Accessed: 20 December 2019)

Alzheimer's Society (no date) *Fix dementia care*. Available at: https://www.alzheimers.org.uk/get-involved/our-campaigns/fix-dementia-care (Accessed: 1 July 2019).

Alzheimer's Society (2019) *Hidden no more: Dementia and disability.* Available at: https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf (Accessed: 28 November 2019)

Andrews, G.J., Cutchin, M., McCracken, K., Phillips, D.R. & Wiles, J. (2007) 'Geographical gerontology: The constitution of a discipline', Social Science & Medicine, vol. 65, no. 1, pp. 151-168.

Andrews, G.J., Evans, J. & Wiles, J.L. (2013) 'Re-spacing and re-placing gerontology: relationality and affect', Ageing & Society, vol. 33, no. 8, pp. 1339-1373.

Andrews, G.J., Gavin, N., Begley, S. & Brodie, D. (2003) 'Assisting friendships, combating loneliness: users' views on a ‘befriending’scheme', Ageing & Society, vol. 23, no. 3, pp. 349-362.

Andrews, G.J., Kearns, R.A., Kontos, P. & Wilson, V. (2006) '‘Their finest hour’: older people, oral histories, and the historical geography of social life', Social & cultural geography, vol. 7, no. 2, pp. 153-177.

Angus, J., Kontos, P., Dyck, I., McKeever, P. & Poland, B. (2005) 'The personal significance of home: habitus and the experience of receiving long-term home care', Sociology of Health & Illness, vol. 27, no. 2, pp. 161-187.

Angus, J. & Reeve, P. (2006) 'Ageism: A threat to “aging well” in the 21st century', Journal of Applied Gerontology, vol. 25, no. 2, pp. 137-152.

Antonucci, T.C., Lansford, J.E. & Akiyama, H. (2001) 'Impact of positive and negative aspects of marital relationships and friendships on well-being of older adults', Applied Developmental Science, vol. 5, no. 2, pp. 68-75.

Baars, J., Dohmen, J. and Grenier, A. (2013) Ageing, meaning and social structure [electronic book] : Connecting critical and humanistic gerontology. Bristol : Policy Press.

Banerjee, S. (2010) 'Living well with dementia—development of the national dementia strategy for England', International journal of geriatric psychiatry, vol. 25, no. 9, pp. 917-922.

Baker, K.L., Robertson, N. & Connelly, D. (2010) 'Men caring for wives or partners with dementia: Masculinity, strain and gain', Aging & mental health, vol. 14, no. 3, pp. 319-327.

Baldassar, L. (2007) 'Transnational families and aged care: the mobility of care and the migrancy of ageing', Journal of ethnic and migration studies, vol. 33, no. 2, pp. 275-297.

Baldwin, C. 2008. Narrative(,) citizenship and dementia: The personal and the political. Journal of Aging Studies, 22, 222-228.

Bamford, C. & Bruce, E. (2000) 'Defining the outcomes of community care: the perspectives of older people with dementia and their carers', Ageing & Society, vol. 20, no. 5, pp. 543-570.

Barnes, C. 2010. What a difference a decade makes: reflections on doing 'emancipatory' disability research. Disability & Society, 18:1, 3-17.

Barnes, R., Auburn, T., Lea, S., 2004. Citizenship in practice. British Journal of Social Psychology, 43, 2, 187.

Bartlett, R. & O'Connor, D. (2007) 'From personhood to citizenship: Broadening the lens for dementia practice and research', Journal of Aging Studies, vol. 21, no. 2, pp. 107-118.

Baxter, P. & Jack, S. (2008) 'Qualitative case study methodology: Study design and implementation for novice researchers', The qualitative report, vol. 13, no. 4, pp. 544-559.

Bazeley, P. & Richards, L. (2000) The NVivo qualitative project book, Sage.

Beeson, R., Horton-Deutsch, S., Farran, C. & Neundorfer, M. (2000) 'Loneliness and depression in caregivers of persons with Alzheimer's disease or related disorders', Issues in Mental Health Nursing, vol. 21, no. 8, pp. 779-806.

BBC (2019) Alzheimer's risk 'different in women and men'. Available at https://www.bbc.co.uk/news/articles/cp03zwze47zo (Accessed: 16 November 2019)

Behuniak, S.M. 2010. Toward a political model of dementia: Power as compassionate care. Journal of Aging Studies, 24, 231-240.

Beresford, P. (2013) ‘Personalisation: From solution to problem’. In: Ferguson., I & Lavalette, M. (ed.). Critical and radical debates in social work [electronic book]: Bristol: Policy Press, 2013, pp. 73-98.

Bhatti, M. (2006) ''When I'm in the garden I can create my own paradise': Homes and gardens in later life', The Sociological Review, vol. 54, no. 2, pp. 318-341.

Bijker, W.E. and Law, J. (1992) Shaping technology/building society. [electronic book] : studies in sociotechnical change. Cambridge, Mass. : MIT Press.

Blaikie, A. (2005) ‘Imagined landscapes of age and identity’. In: Andrews, G.J. and Phillips, D.R. (ed.). Ageing and place : perspectives, policy, practice. London ; Routledge, pp. 164-175

Blunt, A. (2005) 'Cultural geography: cultural geographies of home', Progress in human geography, vol. 29, no. 4, pp. 505-515.

Bond, J. 1992. The Medicalization of Dementia. Journal of ageing studies, 6, 4, 397.

Bond, J. & Corner, L. (2001) 'Researching dementia: are there unique methodological challenges for health services research?', Ageing & Society, vol. 21, no. 1, pp. 95-116.

Bond, J., Stave, C., Sganga, A., Vincenzino, O., O'connell, B. & Stanley, R. (2005) 'Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey', International Journal of Clinical Practice, vol. 59, pp. 8-14.

Boultwood, A. & Jerrard, R. (2000) 'Ambivalence, and its relation to fashion and the body', Fashion theory, vol. 4, no. 3, pp. 301-321.

Bowlby, S. (2011) 'Friendship, co-presence and care: neglected spaces', Social & Cultural Geography, vol. 12, no. 6, pp. 605-622.

Bowlby, S. (2012) 'Recognising the time—space dimensions of care: Caringscapes and carescapes', Environment and Planning A, vol. 44, no. 9, pp. 2101-2118.

Brickell, K. (2012) '‘Mapping’and ‘doing’critical geographies of home', Progress in human geography, vol. 36, no. 2, pp. 225-244.

Brittain, K., Corner, L., Robinson, L. and Bond, J. 2010. Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. Sociology of Health & Illness, 32, 2, 272–287.

Bruens, M.T. (2013) Dementia: beyond structures of medicalisation and cultural neglect. Policy Press.

Bunn, F., Sworn, K., Brayne, C., Iliffe, S., Robinson, L. & Goodman, C. (2015) 'Contextualizing the findings of a systematic review on patient and carer experiences of dementia diagnosis and treatment: a qualitative study', Health Expectations, vol. 18, no. 5, pp. 740-753.

Bunnell, T., Yea, S., Peake, L., Skelton, T. & Smith, M. (2012) 'Geographies of friendships', Progress in Human Geography, vol. 36, no. 4, pp. 490-507.

Burns, A. & Rabins, P. (2000) 'Carer burden in dementia', International Journal of Geriatric Psychiatry, vol. 15, no. S1, pp. S9-S13.

Burrell, K. (2014) 'Spilling over from the street: Contextualizing domestic space in an inner-city neighborhood', Home Cultures, vol. 11, no. 2, pp. 145-166.

Cabinet Office, Department of Health and Social Care, Prime Minister's Office (2015). *Prime Minister's challenge on dementia 2020*. Available at: https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020 (Accessed: 2 December 2019)

Cahill, S., Macijauskiene, J., Nygård, A.-M., Faulkner, J.-P. & Hagen, I. (2007) 'Technology in dementia care', Technology and Disability, vol. 19, no. 2, 3, pp. 55-60.

Cantley, C., Bowes, A. (2004) ‘Dementia and social inclusion. The way forward’. In: Innes, A., Archibald, C., & Murphy, C. (ed.). Dementia and social inclusion: marginalised groups and marginalised areas of dementia research, care and practice. London; Philadelphia: Jessica Kingsley, pp. 255-271.

Care Quality Commission (2018). *The state of health care and adult social care in England 2017/18.* Available at: https://www.gov.uk/government/publications/health-care-and-adult-social-care-in-england-2017-to-2018 (Accessed: 1 December 2019)

Carmody, J., Traynor, V. & Marchetti, E. (2015) 'Barriers to qualitative dementia research: the elephant in the room', Qualitative health research, vol. 25, no. 7, pp. 1013-1019.

Castro, E.M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W. & Van Hecke, A. (2016) 'Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review', Patient education and counseling, vol. 99, no. 12, pp. 1923-1939.

Clarke, A.E., Shim, J.K., Mamo, L., Fosket, J.R. and Fishman, J.R. 2003. Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine. American Sociological Association, 161.

Clarke, C.L. (2001) 'Understanding practice development', A handbook of dementia care, pp. 93-108.

Conrad, P. and Schneider, J.W. (1980) Deviance and medicalization: from badness to sickness. St Louis: Mosby.

Conradson, D. (2003) 'Geographies of care: spaces, practices, experiences', Social & Cultural Geography, vol. 4, no. 4, pp. 451-454.

Coughlin, J.F., D'Ambrosio, L.A., Reimer, B. & Pratt, M.R. (2007) Older adult perceptions of smart home technologies: implications for research, policy & market innovations in healthcare, 2007 29th Annual International Conference of the IEEE Engineering in Medicine and Biology Society, IEEE, pp. 1810-1815.

Cope, M. (2002) 'Feminist epistemology in geography', Feminist geography in practice: Research and methods, pp. 43-56.

Crane, D. (2012) Fashion and its social agendas: Class, gender, and identity in clothing, University of Chicago Press.

Cridland, E.K., Phillipson, L., Brennan-Horley, C. & Swaffer, K. (2016) 'Reflections and recommendations for conducting in-depth interviews with people with dementia', Qualitative Health Research, vol. 26, no. 13, pp. 1774-1786.

Cristoforetti, A., Gennai, F. & Rodeschini, G. (2011) 'Home sweet home: The emotional construction of places', Journal of Aging studies, vol. 25, no. 3, pp. 225-232.

Cutchin, M.P. (2017) Active relationships of ageing people and places, in, Geographical Gerontology: Perspectives, Concepts, Approaches, Routledge, pp. 216-229.

Cutler, S.J. 2005. Ageism and technology. Generations, 29, 3, 67-72.

Czaja, S., Beach, S., Charness, N. & Schulz, R. (2013) Older adults and the adoption of healthcare technology: Opportunities and challenges, in, Technologies for active aging, Springer, pp. 27-46.

Daly, M, & Lewis, J. 2000. 'The concept of social care and the analysis of contemporary welfare states', British Journal Of Sociology, 51, 2, pp. 281-298.

Davies, S. & Nolan, M. (2006) ''Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study', International journal of nursing studies, vol. 43, no. 3, pp. 281-291.

Dening, T. (2016). *Supporting carers of people with dementia*. National Institute for Health Research. Available at: https://www.dc.nihr.ac.uk/highlights/dementia-carers/evidence-at-a-glance.htm (Accessed: 10 December 2019)

DiZazzo-Miller, R. and Pociask, F.D. 2015. Dementia in the Context of Disability. Physical & Occupational Therapy in Geriatrics, 33, 2, 139-151.

Downs, M. 2000. Ageing update. Dementia in a socio-cultural context: An idea whose time has come. Ageing and Society, 20, 3, 369-375.

Dyck, I. (2005) 'Feminist geography, the ‘everyday’, and local–global relations: hidden spaces of place-making', Canadian Geographer/Le Géographe canadien, vol. 49, no. 3, pp. 233-243.

Dyck, I., Kontos, P., Angus, J. & McKeever, P. (2005) 'The home as a site for long-term care: meanings and management of bodies and spaces', Health & place, vol. 11, no. 2, pp. 173-185.

Ebrahim, S. 2002. The Medicalisation Of Old Age: Should Be Encouraged. British Medical Association, 861.

Edwards, R. & Holland, J. (2013) What is qualitative interviewing?, A&C Black.

Estes, C.L. and Binney, E.A. 1989. The biomedicalization of aging: Dangers and dilemmas. The Gerontologist, 29, 5, 587-596.

Etters, L., Goodall, D. & Harrison, B.E. (2008) 'Caregiver burden among dementia patient caregivers: a review of the literature', Journal of the American Academy of Nurse Practitioners, vol. 20, no. 8, pp. 423-428.

Ferguson, I. & Lavalette, M. ‘The crisis in adult social care’. Ferguson., I & Lavalette, M. (ed.). Critical and radical debates in social work [electronic book]: Bristol: Policy Press, 2013, pp. 161-195

Fine, M. & Glendinning, C. (2005) 'Dependence, independence or inter-dependence? Revisiting the concepts of ‘care’and ‘dependency’', Ageing & society, vol. 25, no. 4, pp. 601-621.

Freund, P. 2001. Bodies, Disability and Spaces: The social model and disabling spatial organisations. Disability and Society, 16, 5, 689-706.

Fuller-Iglesias, H., Sellars, B. & Antonucci, T.C. (2008) 'Resilience in old age: Social relations as a protective factor', Research in Human Development, vol. 5, no. 3, pp. 181-193.

Fyfe, N.R. & Milligan, C. (2003) 'Out of the shadows: exploring contemporary geographies of voluntarism', Progress in human geography, vol. 27, no. 4, pp. 397-413.

Gardner, PJ. 2011. 'Natural neighbourhood networks — Important social networks in the lives of older adults aging in place', Journal Of Aging Studies, 25, Special Section: Age and the Cultivation of Place, pp. 263-271.

Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K. & Robinson, L. (2016) 'The provision of assistive technology products and services for people with dementia in the United Kingdom', Dementia, vol. 15, no. 4, pp. 681-701.

Gilleard, C., Hyde, M. & Higgs, P. (2007) 'The impact of age, place, aging in place, and attachment to place on the well-being of the over 50s in England', Research on Aging, vol. 29, no. 6, pp. 590-605.

Gilliard, J., Means, R., Beattie, A. and Daker-White, G. 2005. Dementia care in England and the social model of disability: Lessons and issues. Dementia: The International Journal of Social Research and Practice, 4, 4, 571-586.

Gleeson, B, & Kearns, R. 2001. 'Remoralising landscapes of care', Environment And Planning D-Society & Space, 19, 1, pp. 61-80.

Golant, S.M. (2011) 'The quest for residential normalcy by older adults: Relocation but one pathway', Journal of Aging Studies, vol. 25, no. 3, pp. 193-205.

Golant, S.M. (2017) Explaining the ageing in place realities of older adults, in, Geographical Gerontology, Routledge, pp. 189-202.

Gómez, D.L. (2015) 'Little arrangements that matter. Rethinking autonomy-enabling innovations for later life', Technological forecasting and social change, vol. 93, pp. 91-101.

Gorsky, M, & Mohan, J. 2001, 'London's voluntary hospitals in the interwar period: Growth, transformation, or crisis?',Nonprofit And Voluntary Sector Quarterly, 30, 2, p. 247-275.

Greenwood, N., Mezey, G. & Smith, R. (2018) 'Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness', Maturitas, vol. 112, pp. 39-45.

Guest, G., Bunce, A. & Johnson, L. (2006) 'How many interviews are enough? An experiment with data saturation and variability', Field methods, vol. 18, no. 1, pp. 59-82.

Haan, M.N. & Wallace, R. (2004) 'Can dementia be prevented? Brain aging in a population-based context', Annu. Rev. Public Health, vol. 25, pp. 1-24.

Hanlon, N., Halseth, G., Ostry, A. 2011. Stealth voluntarism: An expectation of health professional work in underserviced areas? Health & Place, 17, 42-49.

Haraway, D.J. (1991) Simians, cyborgs and women : the reinvention of nature. London : Free Association

Harper, S. & Laws, G. (1995) 'Rethinking the geography of ageing', Progress in Human Geography, vol. 19, no. 2, pp. 199-221.

Heath, I. 2000. 'Dereliction Of Duty In An Ageist Society: The Government's Silence Over Royal Commission Report On Long Term Care Is Ominous', BMJ: British Medical Journal, 7247, p. 1422.

Hesse-Biber, S. (2012) 'Feminist approaches to triangulation: Uncovering subjugated knowledge and fostering social change in mixed methods research', Journal of Mixed Methods Research, vol. 6, no. 2, pp. 137-146.

Hill, A. (2019) ‘Dementia care failings cost businesses in England £3.2bn’, The Guardian, 28 September. Available at: https://www.theguardian.com/society/2019/sep/28/dementia-care-failings-cost-businesses-in-england-32bn (Accessed: 17 December 2019)

Holstein, J.A. & Gubrium, J.F. (1995) The active interview, vol. 37, Sage.

Hopkins, P. and Pain, R. 2007. Geographies of age: thinking relationally. Area, 39, 3, 287-294.

Hughes, B. and Paterson, K. 1997. The social model of disability and the disappearing body: Towards a sociology of impairment. Disability and Society, 12, 3, 325-340.

Hulko, W. (2009) 'From ‘not a big deal’to ‘hellish’: experiences of older people with dementia', Journal of Aging studies, vol. 23, no. 3, pp. 131-144.

Jeavons, T.H. (1992) 'When the management is the message: Relating values to management practice in nonprofit organizations', Nonprofit management and leadership, vol. 2, no. 4, pp. 403-417.

Joseph, A.E. & Hallman, B.C. (1998) 'Over the hill and far away: distance as a barrier to the provision of assistance to elderly relatives', Social Science & Medicine, vol. 46, no. 6, pp. 631-639.

Joyce, K., Mamo, L. (2006) ‘Graying the cyborg. New directions in feminist analyses of aging, science and technology’. In: Calasanti, T.M. & Slevin, K.F. (ed) Age matters: realigning feminist thinking. New York; Routledge, pp. 99-121

Joyce, K.A. and Loe, M. (2010) Technogenarians [electronic book] : studying health and illness through an ageing, science, and technology lens / edited by Kelly Joyce and Meika Loe. Chichester: Wiley-Blackwell

Katz, S. (1996) Disciplining old age : the formation of gerontological knowledge. Charlottesville : University Press of Virginia.

Kaufman, S.R., Shim, J.K. and Russ, A.J. 2004. Revisiting the Biomedicalization of Aging: Clinical Trends and Ethical Challenges. The Gerontologist, 44, 6, 731-738.

Keady, J., Campbell, S., Barnes, H., Ward, R., Li, X., Swarbrick, C., Burrow, S. & Elvish, R. (2012) 'Neighbourhoods and dementia in the health and social care context: a realist review of the literature and implications for UK policy development', Reviews in Clinical Gerontology, vol. 22, no. 2, pp. 150-163.

Kearns, A., Andrews, J. (2005) ‘Placing ageing: Positionings in the study of older people’. In: Andrews, G, & Phillips, D. (ed.). Ageing and place. [electronic book]: London: Routledge, 2005, pp. 13-23.

Kearns, R, & Moon, G. 2002, 'From medical to health geography: novelty, place and theory after a decade of change',Progress In Human Geography, 26, 5, pp. 605-625.

Kearns, R. 1993, 'Place and health: Towards a reformed medical geography', Professional Geographer, 45, 2, p. 139.

Kellett, U. (1999) 'Searching for new possibilities to care: A qualitative analysis of family caring involvement in nursing homes', Nursing Inquiry, vol. 6, no. 1, pp. 9-16.

Kendall, J., Knapp, M. (1996) The Voluntary Sector in the UK. Manchester University Press: Manchester.

Kenner, A.M. (2008) 'Securing the Elderly Body: Dementia, Surveillance, and the Politics of" Aging in Place"', Surveillance & Society, vol. 5, no. 3.

Kirk, S. & Glendinning, C. (1998) 'Trends in community care and patient participation: implications for the roles of informal carers and community nurses in the United Kingdom', Journal of Advanced Nursing, vol. 28, no. 2, pp. 370-381.

Kitwood, T. 1989. Brain, Mind and Dementia: With Particular Reference to Alzheimer's Disease. Ageing & Society, 9, 1, 1.

Kitwood, T. (1997) Dementia reconsidered : the person comes first. Buckingham ; Open University Press.

Kitwood, T. and Bredin, K. 1992. Towards a theory of dementia care: personhood and well-being. Ageing and society, 12, 03, 269-287.

Kontos, P. & Martin, W. (2013) 'Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care', Dementia, vol. 12, no. 3, pp. 288-302.

Koss, C. & Ekerdt, D.J. (2016) 'Residential reasoning and the tug of the fourth age', The Gerontologist, vol. 57, no. 5, pp. 921-929.

Kupeli, N., Leavey, G., Harrington, J., Lord, K., King, M., Nazareth, I., Moore, K., Sampson, E.L. & Jones, L. (2018) 'What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective', Dementia, vol. 17, no. 2, pp. 164-179.

Langstrup, H. (2013) 'Chronic care infrastructures and the home', Sociology of health & illness, vol. 35, no. 7, pp. 1008-1022.

Lawson, V. (2007) 'Geographies of care and responsibility', Annals of the Association of American Geographers, vol. 97, no. 1, pp. 1-11.

Lee, V.S., Simpson, J. & Froggatt, K. (2013) 'A narrative exploration of older people's transitions into residential care', Aging & mental health, vol. 17, no. 1, pp. 48-56.

Lloyd, L., Tanner, D., Milne, A., Ray, M., Richards, S., Pat, M., Beech, S. C., Phillips, J. 2014. Look after yourself: active ageing, individual responsibility and the decline of social work with older people in the UK. European Journal of Social Work, 17:3, 322-335.

Loe, M. 2010. Doing it my way: old women, technology and wellbeing. Sociology of Health & Illness, 32, 2, 319–334.

Lorenz, K., Freddolino, P.P., Comas-Herrera, A., Knapp, M. & Damant, J. (2019) 'Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway', Dementia, vol. 18, no. 2, pp. 725-741.

Lorenzen-Huber, L., Boutain, M., Camp, L.J., Shankar, K. & Connelly, K.H. (2011) 'Privacy, technology, and aging: a proposed framework', Ageing International, vol. 36, no. 2, pp. 232-252.

Lyman, K.A. 1989. Bringing the Social Back in - a Critique of the Biomedicalization of Dementia. The Gerontologist, 29, 5, 597-605.

Macmillan, R. & Townsend, A. (2006). 'A 'new institutional fix'? The 'community turn' and the changing role of the voluntary sector'. In: Milligan, C. & Conradson, D. (ed.). Landscapes of voluntarism [electronic book]: Bristol : Policy Press, 2006, pp. 16-32.

Macnicol, J. (2015) Neoliberalising old age. Cambridge: Cambridge University Press.

Mahoney, R., Regan, C., Katona, C. & Livingston, G. (2005) 'Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study', The American Journal of Geriatric Psychiatry, vol. 13, no. 9, pp. 795-801.

McConaghy, R. & Caltabiano, M.L. (2005) 'Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being', Nursing & health sciences, vol. 7, no. 2, pp. 81-91.

McCreadie, C. and Tinker, A. 2005. The acceptability of assistive technology to older people. Ageing and Society, 25, 1, 91-110.

McDowell, L. (1992) 'Doing gender: feminism, feminists and research methods in human geography', Transactions of the institute of British Geographers, pp. 399-416.

McHugh, K.E. 2003. Three faces of ageism: Society, image and place. Ageing and Society, 23, 2, 165-185.

Means, R. (2007) 'Safe as houses? Ageing in place and vulnerable older people in the UK', Social Policy & Administration, vol. 41, no. 1, pp. 65-85.

Mental Capacity Act 2005. Available at: https://www.citethemrightonline.com/gov-eu/uk-statutes (Accessed: 2 November 2014)

Meulenbroek, O., Vernooij-Dassen, M., Kessels, R., Graff, M., Sjögren, M., Schalk, B., Hoogsteen-Ossewaarde, M., Claassen, J., Melis, R. & Rikkert, M.O. (2010) 'Informed consent in dementia research. Legislation, theoretical concepts and how to assess capacity to consent', European Geriatric Medicine, vol. 1, no. 1, pp. 58-63.

Milligan, C. (2000) ''Bearing the burden': towards a restructured geography of caring', Area, vol. 32, no. 1, pp. 49-58.

Milligan, C. (2001) Geographies of care : space, place and the voluntary sector. Ashgate: Aldershot.

Milligan, C. (2003) 'Location or dis-location? Towards a conceptualization of people and place in the care-giving experience', Social & Cultural Geography, vol. 4, no. 4, pp. 455-470.

Milligan, C. (2005) 'From home to ‘home’: situating emotions within the caregiving experience', Environment and planning A, vol. 37, no. 12, pp. 2105-2120.

Milligan, C. (2006) 'Caring for older people in the 21st century: ‘Notes from a small island'', Health & Place, vol. 12, no. 3, pp. 320-331.

Milligan, C. (2007) 'Geographies of voluntarism: mapping the terrain', Geography Compass, vol. 1, no. 2, pp. 183-199.

Milligan, C. (2009) There's No Place Like Home: Place And Care In An Ageing Society. Ashgate: Farnham.

Milligan, C., Atkinson, S., Skinner, M. & Wiles, J. (2007) 'Geographies of care: A commentary', New Zealand Geographer, vol. 63, no. 2, pp. 135-140.

Milligan, C. & Conradson, D. (2006) ‘Contemporary landscapes of welfare: the ‘voluntary turn’?’. In: Milligan, C. & Conradson, D. (ed.). Landscapes of voluntarism [electronic book]: Bristol: Policy Press, 2006, pp. 1-14.

Milligan, C., Gatrell, A. & Bingley, A. (2004) '‘Cultivating health’: therapeutic landscapes and older people in northern England', Social science & medicine, vol. 58, no. 9, pp. 1781-1793.

Milligan, C. & Power, A. (2010) ‘The changing geography of care’. In: Tim Brown, T., McLafferty, S., & Moon, G. (ed). A companion to health and medical geography [electronic book]: Wiley-Blackwell: Chichester, West Sussex, 2010, pp. 567-586.

Milligan, C., Roberts, C. & Mort, M. (2011) 'Telecare and older people: who cares where?', Social science & medicine, vol. 72, no. 3, pp. 347-354.

Milligan, C. & Wiles, J. (2010) 'Landscapes of care', Progress in Human Geography, vol. 34, no. 6, pp. 736-754.

Mitzner, T.L., Boron, J.B., Fausset, C.B., Adams, A.E., Charness, N., Czaja, S.J., Dijkstra, K., Fisk, A.D., Rogers, W.A. and Sharit, J. 2010. Older adults talk technology: Technology usage and attitudes. Computers in Human Behavior , 26, 1710–1721.

Mohan, J. 2012. Geographical foundations of the Big Society. Environment and Planning A., 44, 1121–1129.

Mort, M., Roberts, C., Callen, B. 2013. Ageing with telecare: care or coercion in austerity? Sociology of health & illness, 35, 6, 799.

Mullan, P. (2000) The imaginary time bomb: why an ageing population is not a social problem. I.B. Taurius: London ; New York.

Neven, L. 2010. 'But obviously not for me': Robots, laboratories and the defiant identity of elder test users. Sociology of Health and Illness, 32, 2, 335-347.

Nolan, M.R., Davies, S., Brown, J., Keady, J. & Nolan, J. (2004) 'Beyond ‘person-centred’care: a new vision for gerontological nursing', Journal of clinical nursing, vol. 13, pp. 45-53.

Oldman, C. (2002) 'Later life and the social model of disability: a comfortable partnership?', Ageing & Society, vol. 22, no. 6, pp. 791-806.

Orgeta, V., Mukadam, N., Sommerlad, A. & Livingston, G. (2019) 'The Lancet commission on dementia prevention, intervention, and care: a call for action', Irish journal of psychological medicine, vol. 36, no. 2, pp. 85-88.

Orr, D.M. & Teo, Y. (2015) 'Carers’ responses to shifting identity in dementia in Iris and Away From Her: cultivating stability or embracing change?', Medical Humanities, vol. 41, no. 2, pp. 81-85.

Östlund, B. 2004. Social Science Research on Technology and the Elderly -- Does it Exist? Science Studies, 17, 2, 44-62.

Oudshoorn, N. (2011) Telecare technologies and the transformation of health care [electronic book]. Palgrave Macmillan: Basingstoke.

Pain, R., Mowl, G. and Talbot, C. 2000. Difference and the negotiation of 'old age'. Environment and Planning D: Society and Space, 18, 3, 377-393.

Parker, S.G. and Hawley, M.S. 2013. Telecare for an ageing population? Age and Ageing, 42, 4, 424-425.

Parkin, E. & Baker, C. (2016) 'Dementia: Policy, services and statistics', Commons Briefing Paper SN07007, esearchbriefings. parliament. uk/ResearchBriefing/Summary/SN07007# fullreport, Posted, vol. 14.

Parr, H. 2002, 'Medical geography: diagnosing the body in medical and health geography, 1999–2000', Progress In Human Geography, 26, 2, pp. 240-251.

Peek, S.T., Luijkx, K.G., Rijnaard, M.D., Nieboer, M.E., van der Voort, C.S., Aarts, S., van Hoof, J., Vrijhoef, H.J. & Wouters, E.J. (2016) 'Older adults' reasons for using technology while aging in place', Gerontology, vol. 62, no. 2, pp. 226-237.

Peel, E. 2014. 'The living death of Alzheimer's' versus 'Take a walk to keep dementia at bay': Representations of dementia in print media and carer discourse. Sociology of Health and Illness, 36, 6, 885–901.

Peine, A., Faulkner, A., Jæger, B. & Moors, E. (2015) Science, technology and the ‘grand challenge’of ageing—Understanding the socio-material constitution of later life, Elsevier.

Peine, A. & Herrmann, A.M. (2012) 'The sources of use knowledge: Towards integrating the dynamics of technology use and design in the articulation of societal challenges', Technological Forecasting and Social Change, vol. 79, no. 8, pp. 1495-1512.

Peine, A., Rollwagen, I. & Neven, L. (2014) 'The rise of the “innosumer”—rethinking older technology users', Technological forecasting and social change, vol. 82, pp. 199-214.

Percival, J. and Hanson, J. 2006. Big brother or brave new world? Telecare and its implications for older people's independence and social inclusion. Critical Social Policy, 26, 4, 888-909.

Phillips, J. (2007). Care. Polity Press: Cambridge

Phillips, R. & Evans, B. (2018) 'Friendship, curiosity and the city: Dementia friends and memory walks in Liverpool', Urban studies, vol. 55, no. 3, pp. 639-654.

Pierson, C. (1994). Beyond the welfare state? The new political economy of welfare. Polity Press: Cambridge.

Poland, B, Lehoux, P, Holmes, D, & Andrews, G. 2005, 'How place matters: unpacking technology and power in health and social care', Health & Social Care In The Community, 13, 2, pp. 170-180.

Pols, J. (2012) Care at a Distance, in, On the Closeness of Technology, Amsterdam University Press.

Power, A. (2010). Landscapes of care: comparative perspectives on family caregiving. [electronic book]. Burlington, VT : Ashgate.

Riley, L.D. & Bowen, C.P. (2005) 'The sandwich generation: Challenges and coping strategies of multigenerational families', The Family Journal, vol. 13, no. 1, pp. 52-58.

Ritchie, J. & Spencer, L. (2002) Qualitative data analysis for applied policy research, in, Analyzing qualitative data, Routledge, pp. 187-208.

Robert, G., Greenhalgh, T., MacFarlane, F. & Peacock, R. (2010) 'Adopting and assimilating new non-pharmaceutical technologies into health care: a systematic review', Journal of health services research & policy, vol. 15, no. 4, pp. 243-250.

Roberts, C. & Mort, M. (2009) 'Reshaping what counts as care: Older people, work and new technologies', ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap, vol. 3, no. 2, pp. 138-158.

Robinson, C.A., Bottorff, J.L., Pesut, B., Oliffe, J.L. & Tomlinson, J. (2014) 'The male face of caregiving: A scoping review of men caring for a person with dementia', American journal of men's health, vol. 8, no. 5, pp. 409-426.

Robinson, F. (1997) 'Globalizing care: Ethics, feminist theory, and international relations', Alternatives, vol. 22, no. 1, pp. 113-133.

Robinson, L., Brittain, K., Lindsay, S., Jackson, D. and Olivier, P. 2009. Keeping in Touch Everyday (KITE) project: Developing assistive technologies with people with dementia and their carers to promote independence. International Psychogeriatrics, 21, 3, 494-502.

Robinson, L., Tang, E. & Taylor, J.-P. (2015) 'Dementia: timely diagnosis and early intervention', Bmj, vol. 350, p. h3029.

Rooksby, J., Rost, M., Morrison, A. & Chalmers, M. (2014) Personal tracking as lived informatics, Proceedings of the SIGCHI conference on human factors in computing systems, ACM, pp. 1163-1172.

Rose, G. (1997) 'Situating knowledges: positionality, reflexivities and other tactics', Progress in human geography, vol. 21, no. 3, pp. 305-320.

Rose, N. 2007. Beyond medicalisation. The Lancet, 9562.

Roulstone, A. (2013) ‘Personalisation – plus ca change?’. In: Ferguson., I & Lavalette, M. (ed.). Critical and radical debates in social work [electronic book]: Bristol: Policy Press, 2013, pp. 119-123

Rowles, G.D. (1986) 'The geography of ageing and the aged: toward an integrated perspective', Progress in Human Geography, vol. 10, no. 4, pp. 511-539.

Rowles, G.D. (1993) 'Evolving images of place in aging and ‘aging in place’', Generations, vol. 17, no. 2, pp. 65-70.

Rowles, G.D. (2017) Being in place: Identity and place attachment in late life, in, Geographical Gerontology, Routledge, pp. 203-215.

Rowles, G.D., Oswald, F. & Hunter, E.G. (2003) 'Interior living environments in old age', Annual review of gerontology and geriatrics, vol. 23, no. 1, pp. 167-194.

Rowles, G.D. & Ravdal, H. (2002) 'Aging, place, and meaning in the face of changing circumstances', Challenges of the third age: Meaning and purpose in later life, pp. 81-114.

Sampson, M.S. & Clark, A. (2016) '‘Deferred or chickened out?’Decision making among male carers of people with dementia', Dementia, vol. 15, no. 6, pp. 1605-1621.

Sanford, S., Rapoport, M.J., Tuokko, H., Crizzle, A., Hatzifilalithis, S., Laberge, S., Naglie, G., Driving, C.C.o.N.i.A. & Team, D. (2019) 'Independence, loss, and social identity: perspectives on driving cessation and dementia', Dementia, vol. 18, no. 7-8, pp. 2906-2924.

Schulz, R., Beach, S.R., Matthews, J.T., Courtney, K., De Vito Dabbs, A. & Mecca, L.P. (2015) 'Caregivers’ willingness to pay for technologies to support caregiving', The Gerontologist, vol. 56, no. 5, pp. 817-829.

Schwanen, T, Hardill, I, & Lucas, S. 2012, 'Spatialities of ageing: The co-construction and co-evolution of old age and space', Geoforum, 43, Themed issue: Spatialities of Ageing, pp. 1291-1295.

Sevenhuijsen, S. (2003) 'The place of care: The relevance of the feminist ethic of care for social policy', Feminist theory, vol. 4, no. 2, pp. 179-197.

Shah, H., Albanese, E., Duggan, C., Rudan, I., Langa, K.M., Carrillo, M.C., Chan, K.Y., Joanette, Y., Prince, M. & Rossor, M. (2016) 'Research priorities to reduce the global burden of dementia by 2025', The Lancet Neurology, vol. 15, no. 12, pp. 1285-1294.

Shank, K.S.H. & Cutchin, M.P. (2016) 'Processes of developing ‘community livability’in older age', Journal of aging studies, vol. 39, pp. 66-72.

Sihto, T. (2018) 'Distances and proximities of care: Analysing emotio-spatial distances in informal caring', Emotion, Space and Society, vol. 29, pp. 62-68.

Skinner, M.W., Cloutier, D. & Andrews, G.J. (2015) 'Geographies of ageing: Progress and possibilities after two decades of change', Progress in Human Geography, vol. 39, no. 6, pp. 776-799.

Skinner, M, & Fleuret, S. 2011, 'Health geography’s voluntary turn: A view from western France', Health And Place, 17, Health Geographies of Voluntarism, pp. 33-41.

Skinner, M.W., Joseph, A.E., Hanlon, N., Halseth, G. & Ryser, L. (2014) 'Growing old in resource communities: Exploring the links among voluntarism, aging, and community development', The Canadian Geographer/Le Géographe canadien, vol. 58, no. 4, pp. 418-428.

Skinner, M, & Power, A. 2011, 'Voluntarism, health and place: Bringing an emerging field into focus', Health & Place, 17, 1, pp. 1-6.

Sörensen, S., Duberstein, P., Gill, D. & Pinquart, M. (2006) 'Dementia care: mental health effects, intervention strategies, and clinical implications', The Lancet Neurology, vol. 5, no. 11, pp. 961-973.

Spijker, J. and MacInnes, J. 2013. Population ageing: the timebomb that isn’t? BMJ, 347, 1-5.

Sutcliffe, C.L., Roe, B., Jasper, R., Jolley, D. & Challis, D.J. (2015) 'People with dementia and carers’ experiences of dementia care and services: Outcomes of a focus group study', Dementia, vol. 14, no. 6, pp. 769-787.

Tarrant, A. (2014) 'Negotiating multiple positionalities in the interview setting: researching across gender and generational boundaries', The Professional Geographer, vol. 66, no. 3, pp. 493-500.

Taylor-Gooby, P. 2012. Root and Branch Restructuring to Achieve Major Cuts: The Social Policy Programme of the 2010 UK Coalition Government. Social Policy & Administration, 46, 1, pp. 61-82.

Thapar-Björkert, S. & Henry, M. (2004) 'Reassessing the research relationship: Location, position and power in fieldwork accounts', International Journal of Social Research Methodology, vol. 7, no. 5, pp. 363-381.

Timmermans, S. & Berg, M. The practice of medical technology. Sociology of Health & Illness, 25 Silver Anniversary Issue, pp. 97–114.

Trnka, S. & Trundle, C. (2014) Competing responsibilities: Moving beyond neoliberal responsibilisation, Anthropological Forum, vol. 24, Taylor & Francis, pp. 136-153.

Twigg, J. (2000) 'Carework as a form of bodywork', Ageing & Society, vol. 20, no. 4, pp. 389-411.

Tyrrell, N. (2019) ‘First council built care home in decades opens in Liverpool’, Liverpool Echo, 25 October. Available at: https://www.liverpoolecho.co.uk/news/liverpool-news/first-council-built-care-home-17147004 (Accessed: 17 December 2019)

Warren, M. (2007) 'The digital vicious cycle: Links between social disadvantage and digital exclusion in rural areas', Telecommunications Policy, vol. 31, no. 6-7, pp. 374-388.

Watson, N, McKie, L, Hughes, B, Hopkins, D, & Gregory, S 2004, '(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model', Sociology, 2, p. 331.

Webster, A 2002, 'Innovative Health Technologies and the Social: Redefining Health, Medicine and the Body', Current Sociology, 50, 3, p. 443.

Welsh Government (2018) *Dementia Action Plan for Wales 2018-2022.* Available at: https://gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf (Accessed: 20 October 2019)

Wherton, J., Sugarhood, P., Procter, R. & Greenhalgh, T. (2015) 'Designing technologies for social connection with older people', Aging and the Digital Life Course, vol. 3, p. 107.

Wiles, J. (2003) 'Daily geographies of caregivers: mobility, routine, scale', Social Science & Medicine, 57, pp. 1307-1325.

Wiles, J. (2003) 'Informal caregivers’ experiences of formal support in a changing context', Health & social care in the community, vol. 11, no. 3, pp. 189-207.

Wiles, J. (2005) 'Conceptualizing place in the care of older people: the contributions of geographical gerontology', Journal of Clinical Nursing, vol. 14, pp. 100-108.

Wiles, J.L. (2017) '3 Health geographies of ageing', Geographical Gerontology: Perspectives, Concepts, Approaches.

Wiles, J.L., Leibing, A., Guberman, N., Reeve, J. & Allen, R.E. (2012a) 'The meaning of “aging in place” to older people', The gerontologist, vol. 52, no. 3, pp. 357-366.

Wiles, J.L., Wild, K., Kerse, N. & Allen, R.E. (2012b) 'Resilience from the point of view of older people:‘There's still life beyond a funny knee’', Social Science & Medicine, vol. 74, no. 3, pp. 416-424.

Wilkinson, H. (2002) Including people with dementia in research: Methods and Motivations. In; Wilkinson, H.(ed.) The perspectives of people with dementia research methods and motivations, Jessica Kingsley Publishers: London.

Williams, A. 2002, 'Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space', Social Science & Medicine, 55, pp. 141-154.

Williams, A. & Crooks, V.A. (2008) 'Introduction: Space, place and the geographies of women's caregiving work'.

Wolch, J. (1989) The power of geography: how territory shapes social life, London: Unwin Hyman.

Wolch, J. (2006) Foreword: Beyond the Shadow State? In Milligan, C. & Conradson, D. (eds.). Landscapes of Voluntarism, Bristol: The Policy Press, University of Bristol.

Woolhead, G., Calnan, M., Dieppe, P. & Tadd, W. (2004) 'Dignity in older age: what do older people in the United Kingdom think?', Age and ageing, vol. 33, no. 2, pp. 165-170.

Yin, R.K. (2015) Qualitative research from start to finish, Guilford Publications.

Appendices

Appendix 1. Questions for people with dementia

Interview Schedule 1.1. Technology

1. Please tell me about your device/gadget you are using or the system installed in your home
2. Can you tell me a bit about your experiences of assistive technology?
3. How do you use the device/system and what does it do?
4. What made you want to try this item?
5. Can you tell me about any expectations you may have had before the system was put in/technology item provided?
6. Does the tech do what you expected it to do?
7. Has anything changed for you since it was installed/provided? How? Are things better, worse or the same?
8. Has you home environment changed in any way? Has your personal space been affected?
9. For telecare users: who is on the other end? What would they do in an emergency?
10. What does it feel like being connected to family carers/call centre staff/other through the system?
11. Who else do you think may find this technology useful and why?
12. What would you change about the system/item and why?
13. Do you do most things around the house alone? Do you need help with anything?
14. Does anyone help you with the technology and how?
15. What works well, what doesn't work and what could work better?

Interview Schedule 1.2 Befriending

1. Can you tell me about your experience of befriending?
2. Can we talk about the befriending visits? What do you do when you befriender comes?

3. How did you find out about the befriending scheme? How long did it take the scheme staff to find a befriender for you?
4. Can you tell me why you decided to have the befriending visits?
5. Have you had more than one befriender?
6. Is this number of visits per week/month good for you?
7. Which places do you visit with your befriender? Who chooses where to go?
8. Do you think schemes like this one should be free of cost or should they charge for the visits?
9. Do you know of any other befriending schemes in Liverpool?
10. How do you think these visits affect your family member? What do they do when you are with your befriender?

Appendix 2. Questions for family carers

Interview schedule 2.1. Introduction questions

1. Please tell me for how long you have been caring for …..
2. Are you his/her sole carer/primary carer?
3. Which support services are you currently accessing/using (private/statutory/voluntary)?
4. Have you had a carer's needs assessment?
5. Can you describe your journey as a carer? (Prior and post-diagnosis)
6. Can you describe your needs, experiences and challenges of caring for the person living with dementia?

Schedule 2.2. Technological support

1. Please tell me about your device/gadget you are using or the system installed in your home
2. Can you tell me a bit about your experiences of assistive technology?
3. How did you find out about this item/system?
4. How do you use it and what does it do?
5. Can you talk to me about your experience of the assessment process?
6. What made you want to try this item?
7. What happens when things do not work properly?
8. Can you tell me about any expectations you may have had before the system was put in/technology item provided?
9. Does the tech do what you expected it to do?
10. Has anything changed for you since it was installed/provided? How? Are things better, worse or the same?
11. Has the installed system changed the home environment in any way?
12. For telecare users: what happens when you receive an alert?
13. What does it feel like being connected to the person you care for through this system?
14. Who else do you think may find this technology useful and why?

15. What would you change about the system/item and why?
16. Does anyone help you with the technology and how?
17. What works well, what doesn't work and what could work better?
18. What would have happened had you not had the system installed?

Schedule 2.3. Voluntary support

1. How did you find out about the befriending scheme?
2. How long did it take the scheme staff to find a befriender for your family member?
3. Can you tell me about your experience of befriending?
4. Do you receive any support from other voluntary organisations?
5. Can you tell me why you decided to have the befriending visits?
6. Have you had more than one befriender?
7. Is this number of visits per week/month good for you?
8. Do you think schemes like this one should be free of cost or should they charge for the visits?
9. Do you know of any other befriending schemes in Liverpool?
10. How do you imagine an 'ideal' befriender?
11. What would have happened had you not received befriending support from the scheme?
12. What happens when a visit gets cancelled?
13. If your current befriender no longer can visit your family member, would you ask the scheme to find another volunteer?
14. Is continuity of befriending visits important to you? Why?

Schedule 2.4. Care

1. Do you define yourself as a 'carer'? What does being a carer mean to you?
2. What does 'care' and 'care' mean to you?
3. Depending on the living arrangements: how does the distance/living apart affect your relationship with the person you care for?

Appendix 3. Questions for volunteer befrienders

1. Please tell me about your befriending visits – how often do you visit and what do you do during the visits?
2. In which areas of Liverpool do your visits take place? Why in those areas?
3. How far do you have to travel for your visits?
4. Can you tell me how you were matched with your befriendees?
5. Can you tell me why you have decided to volunteer for this Befriending scheme?
6. Do you know of any other similar organisations/services in Liverpool?
7. Have you been asked to introduce assistive technology items to befriendees and carers by the scheme staff? How did you feel about it?
8. The case partner's service which incorporates this Befriending scheme focuses on the reduction of health inequalities in Liverpool through awareness raising and community engagement activities. Have you been asked to spread the 'health and wellbeing message' to your befriendees and carers? How did you feel about it?
9. Have you been asked to refer your befriendee and carers to other services?
10. For those who use reminiscence apps at visits: how do you use the app and what does it do?
11. Do you use other gadgets during your befriending visits?
12. What community resources do you access with your Befriendee?
13. How do you think your befriending support has enabled the person with dementia access community resources?
14. Would they have connected to the community resources without the Befriending support?
15. Have you discussed 'the exit strategy' with the scheme staff for the time when you are no longer available for befriending visits?
16. Do you know of other older people with dementia who are currently not being supported by the scheme?
17. Do you have any health and safety, safeguarding and reporting responsibilities? Can you tell me about them?
18. What do you get out of doing the befriending?

19. How would the carer and the befriendee have coped without the support of volunteer befrienders?
20. Has your support had an impact on the care relationship? If yes, can you describe it?
21. Has the use of technology had an impact on your relationship with the person with dementia? Carer? Please describe it.
22. Is befriending different to friendship?
23. What is the role of the befriender within the network of care?

Appendix 4. Questions for case partner’s staff

1. Please tell me about your role with the case partner, how long have you worked for the service and what your role entails.
2. If you have or are currently working with befrienders, people living with dementia and carers, in what capacity?
3. What do you mean by assistive technologies and systems?
4. How did you learn about assistive technologies (types, needs, design, use, maintenance)? What kind of assistive technology training have you undertaken?
5. What is your favourite assistive technology item/system?
6. Why do you think some technologies are adopted quickly while others are abandoned?
7. Has your role changed in any way since the introduction of assistive technologies/systems into your working environment? How?
8. How would you describe ‘an ideal’ assistive technology item or system?
9. Can you describe an assistive technology user to me?
10. In your opinion, what are the barriers to the adoption of assistive technologies?
11. What is the role of volunteer befrienders in relation to the assistive tech work carried out by the befriending service?
12. Are there any disadvantages to assistive technologies? What are they?
13. Do you know of any other organisations or services in Liverpool who do similar work to the organisation – volunteering, befriending, tackling health inequalities and working with assistive technologies?
14. What do you think of this model (the mix of voluntary care and assistive technology provision)?
15. Case partner’s service which incorporates the befriending project focuses on the reduction of health inequalities in Liverpool through awareness raising and community engagement activities. What do you think the role of volunteers is in relation to these objectives?
16. What do you think the role of voluntary organisations is/should be in the delivery of social care services?

17. What do you think the role of voluntary organisations is/should be in the delivery of **dementia care** services?

Appendix 5. Questions for technology developers

1. Please tell me about your organisation, your role, how long have you worked for the organisation and what your role entails.
2. Tell me about your work with (assistive) technologies.
3. What do you mean by assistive technologies and systems?
4. What kind of care does your product deliver (physical, social, checking in)?
5. Assistive technologies within the current socio-economic climate: their role in health and social care
6. What problems in healthcare do innovators promise to solve? What scenarios about healthcare are articulated in promises about (telecare) technologies?
7. What roles are defined, and for whom? Who is expected to care for and with telecare technologies?
8. Whose needs and worries are addressed? Whose perspectives on care and illness are taken into account?
9. The role of assistive tech in supporting people living mental impairments, including dementia
10. How did you learn about assistive technologies (types, needs, design, use, maintenance)? What kind of assistive technology training have you undertaken?
11. What is your favourite assistive technology item/system?
12. Why do you think some technologies are adopted quickly while others are abandoned?
13. How would you describe ‘an ideal’ assistive technology item or system?
14. Can you describe an assistive technology user to me?
15. In your opinion, what are the barriers to the adoption of assistive technologies?
16. Can you tell me about benefits and disadvantages of assistive technologies?
17. What do you think the role of voluntary organisations should be in the delivery of social care services?
18. What do you think the role of voluntary organisations is/should be in the delivery of dementia care services?

Appendix 6. Consent form for carers

Committee on Research Ethics

PARTICIPANT CONSENT FORM (CARERS)

Title of Research Project: Proximities of Care: Exploring the spatial relations of voluntary and technological support for those living with dementia

Researcher(s): Lena O'Connell

Please initial box

1. I confirm that I have read and have understood the information sheet dated [DATE] 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 rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

3. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐

4. I understand and agree that my participation will be audio recorded and I am aware of and consent to your use of these recordings for the following purpose: to inform the direction of research and to generate new reseach themes. ☐

5. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. ☐

6. I agree to take part in the following research activities:

   - Participant Observations

- Interviews/audio recording ☐
- Keeping a diary ☐
- Focus groups ☐ ☐

______________________________ ________ __________________

Participant Name Date Signature

______________________________ ________ __________________

Name of Person taking consent Date Signature

______________________________ ________ __________________

Researcher Date Signature

Student Researcher: Lena O’Connell Department of Geography and Planning, 104, Roxby Building University of Liverpool L69 7ZT. Tel: 0151 795 2880Email: yelenam@liv.ac.uk

Supervisors: Dr Bethan Evans bevans@liverpool.ac.uk Dr Mark Riley rileym@liverpool.ac.uk

Prof. Christine Milligan c.milligan@lancaster.ac.uk

Appendix 7. Consent form for people with dementia

Committee on Research Ethics

PARTICIPANT CONSENT FORM

Title of Research Project: The role of technologies in care

Researcher(s): Lena O’Connell

Please tick the box

7. I confirm that I have read and have understood the information sheet dated 23/11/2016 for the above study. I have had the opportunity to consider the information and ask questions. ☐

8. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

9. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐

10. I understand and agree that my participation will be audio recorded and I am aware of and consent to your use of these recordings for the following purpose: to inform the direction of research and to generate new reseach themes. ☐

11. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. ☐

12. I agree to take part in the following research activities:

- Participant Observations ☐

- Interviews/audio recording ☐
- Keeping a diary ☐

Participant Name Date Signature

Name of Person taking consent Date Signature

Researcher Date Signature

Student Researcher: Lena O'Connell Department of Geography and Planning, 104, Roxby Building University of Liverpool L69 7ZT. Tel: 0151 795 2880 Email: yelenam@liv.ac.uk

Supervisors: Dr Bethan Evans: bevans@liverpool.ac.uk Dr Mark Riley: rileym@liverpool.ac.uk Prof. Christine Milligan: c.milligan@lancaster.ac.uk

Appendix 8. Consent form for volunteer befrienders

Committee on Research Ethics

PARTICIPANT CONSENT FORM (VOLUNTEER BEFRIENDERS)

Title of Research Project: Proximities of Care: Exploring the spatial relations of voluntary and technological support for those living with dementia

Researcher(s): Lena O'Connell

Please initial box

13. I confirm that I have read and have understood the information sheet dated [DATE] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

14. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

15. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐

16. I understand and agree that my participation will be audio recorded and I am aware of and consent to your use of these recordings for the following purpose: to inform the direction of research and to generate new reseach themes. ☐

17. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. ☐

18. I agree to take part in the following research activities:

- Participant Observations ☐
- Interviews/audio recording ☐
- Keeping a diary ☐

Participant Name	Date	Signature
Name of Person taking consent	Date	Signature
Researcher	Date	Signature

Student Researcher: Lena O’Connell Department of Geography and Planning, 104, Roxby Building University of Liverpool L69 7ZT. Tel: 0151 795 2880Email: yelenam@liv.ac.uk

Supervisors: Dr Bethan Evans bevans@liverpool.ac.uk Dr Mark Riley rileym@liverpool.ac.uk Prof. Christine Milligan c.milligan@lancaster.ac.uk

Appendix 9. Information sheet for people with dementia

23/11/2016

Dear

My name is Lena and I am a studying for a PhD at the University of Liverpool in collaboration with PSS. I would like to invite you to take part in my research titled **'The role of technologies in provision of social care'.** The study will explore how volunteers can support people living with memory difficulties and their carers. The study will also look at what role assistive technologies can play in supporting people with memory challenges.

Your opinions will be very valuable for my research and will hopefully improve support services provided by PSS. I hope you will accept my invitation and share your views on the subject.

Please note that you are free to withdraw at any time without explanation and without any disadvantage to you.

I would like to ask you to participate in an interview with me which will last for no longer than an hour. The interview will be audio recorded, but if you are unhappy with this I will take notes instead. If you would like to see the transcript of the interview, please let me know and I will provide it. Some parts of the transcripts may be published in academic journals, however your name or any other information that could identify you will not be used. This will be a one to one interview, but if you would like your carer to be present in the house during the interview, or join our conversation just let me know.

I do not expect any disadvantages arising from the activity but if you would like to talk to me about this, please let me know. If you are unhappy, or if there is a problem, please let me know. You can call me on **0151 795 2808** or e-mail me on **yelenam@liverpool.ac.uk**. Also, please feel free to contact my supervisor, Dr Bethan Evans on **0151 794 2881** or

bevans@liv.ac.uk and she will try to help.

If you have a complaint with which you feel you cannot come to us, please speak to the Research Governance Officer at ethics@liv.ac.uk. Please tell them the name or description of the study, the researcher(s) involved, and the details of the complaint you wish to make. Please feel free to ask me if you would like more information. **I would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.**

Thank you for reading this.

Lena O’Connell

Postgraduate Researcher

Department of Geography and Planning

University of Liverpool

e-mail: yelenam@liverpool.ac.uk Tel: 0151 795 2808

Project supervisors: Dr Bethan Evans, Dr Mark Riley Department of Geography and Planning, University of Liverpool; Prof Christine Milligan, Division of Health Research, Lancaster University

Appendix 10. Information sheet for family carers

Dear

My name is Lena and I am a studying for a PhD at the University of Liverpool in collaboration with PSS. I would like to invite you to take part in my research study titled Proximities of Care: Exploring the spatial relations of voluntary and technological support for those living with dementia. The study will explore technologically supported care provision for people living with dementia and their carers. The project is funded by the Economic and Social Research Council.

Your insight and perspective as a carer will be very valuable for my research as it will inform a better understanding of dementia care provision supported by voluntary organisations and assistive technologies. I hope you will accept my invitation and share your views on the subject. **Please note that you are free to withdraw at any time without explanation and without incurring a disadvantage.**

I would like to ask you to participate in an interview with me which will last no longer than an hour. I will ensure that date and time of the interview are suitable for you and do not cause you any inconvenience. If you are happy for me to do so, I would like to audio record the interview so that I don't have to take notes. The recording would then be transcribed. I can send the transcript to you for review to ensure its accuracy, if you would like me to do this – please just let me know. Some aspects of the transcripts may be used for publication in academic journals, however your responses will be anonymised, your name or any other information that could potentially identify you will not be used.

I do not anticipate any risks or disadvantages arising from the interview or the discussion, however, if you feel you would like to discuss this further, please let me know. In terms of benefits, in the long term this research may contribute to the improvement of dementia care in Liverpool.

If you are unhappy, or if there is a problem, please let me know. You can e-mail me on **yelenam@liverpool.ac.uk**. Also, please feel free to contact my supervisor, Dr Bethan Evans on **0151 794 2881** or bevans@liv.ac.uk and she will try to help. If you are still unhappy or have a complaint with which you feel you cannot come to us, then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Please feel free to ask me if you would like more information or if there is anything that you do not understand. I would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. Thank you for reading this.

Yours sincerely,

Lena O'Connell

Postgraduate Researcher

Department of Geography and Planning

University of Liverpool

e-mail: yelenam@liverpool.ac.uk

Tel: 0151 795 2808

Project supervisors: Dr Bethan Evans, Dr Mark Riley Department of Geography and Planning, University of Liverpool; Prof Christine Milligan, Division of Health Research, Lancaster University

Appendix 11. Information sheet for volunteer befrienders

Dear

My name is Lena and I am a studying for a PhD at the University of Liverpool in collaboration with PSS. I would like to invite you to take part in my research study titled Proximities of Care: Exploring the spatial relations of voluntary and technological support for those living with dementia. The study will explore technologically supported care provision for people living with dementia and their carers. The project is funded by the Economic and Social Research Council.

Your insight and perspective as a volunteer befriender will be very valuable for my research as it will inform a better understanding of dementia support services provided by PSS. I hope you will accept my invitation and share your views on the subject. **Please note that you are free to withdraw at any time without explanation and without incurring a disadvantage.**

I would like to ask you to participate in an interview with me. I anticipate that the interview should last no longer than an hour. I will ensure that dates and times of these activities are suitable for you and do not cause you any inconvenience. If you are happy for me to do so, I would like to audio record the interview so that I don't have to take notes. The recording would then be transcribed. I will send the transcript to you for review to ensure its accuracy if you would like to do this – please just let me know. Some aspects of the transcripts may be used for publication in academic journals, however your responses will be anonymised, your name or any other information that could potentially identify you will not be used.

I do not anticipate any risks or disadvantages arising from the interview or the discussion, however, if you feel you would like to discuss this further, please let me know. In terms of benefits, in the long term this research may contribute to the improvement of dementia services provided by PSS.

If you are unhappy, or if there is a problem, please let me know. You can e-mail me on **yelenam@liverpool.ac.uk**. Also, please feel free to contact my supervisor, Dr Bethan Evans on **0151 794 2881** or bevans@liv.ac.uk and she will try to help. If you are still unhappy or have a complaint with which you feel you cannot come to us, then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Please feel free to ask me if you would like more information or if there is anything that you do not understand. I would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. Thank you for reading this.

Yours sincerely,

Lena O’Connell

Postgraduate Researcher

Department of Geography and Planning

University of Liverpool

e-mail: yelenam@liverpool.ac.uk

Tel: 0151 795 2808

Project supervisors: Dr Bethan Evans, Dr Mark Riley Department of Geography and Planning, University of Liverpool; Prof Christine Milligan, Division of Health Research, Lancaster University

Appendix 12. Information sheet for professionals and members of staff at the case partner organisation

Dear

You are being invited to take part in a research study titled Proximities of Care: Exploring the spatial relations of voluntary and technological support for those living with dementia. The study will explore technologically supported care provision for people living with dementia and their carers. The project is funded by the Economic and Social Research Council with the researcher based at Liverpool University.

In order to better understand the debates surrounding voluntary provision of care supported by assistive technologies, I have identified individuals who may have an interesting perspective on the subject. I hope you will accept my invitation and share your views on the matter. Please note that you are free to withdraw at any time without explanation and without incurring a disadvantage.

Your responses will be anonymised, your name or any other information that could potentially identify you will not be used. The interview will be audio recorded and transcribed, I will send the transcript to you for review to ensure its accuracy. If there are any questions that you would rather not answer, please tell me and I will move on to another topic. Some aspects of the transcripts may be used for publication in academic journals, however identities of the respondents will not be disclosed.

I do not anticipate any risks or disadvantages arising from the interview, however, if you feel you would like to discuss this further, please let me know. In terms of benefits, in the long term this research may contribute to the improvement of dementia care in Liverpool.

If you are unhappy, or if there is a problem, please let me know. You can e-mail me on yelenam@liverpool.ac.uk. Also, please feel free to contact my supervisor, Dr Bethan Evans on 0151 794 2881 or bevans@liv.ac.uk and she will try to help. If you are still unhappy or have a complaint with which you feel you cannot come to us, then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Please feel free to ask me if you would like more information or if there is anything that you do not understand. I would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. Thank you for reading this.

Yours sincerely,

Lena O’Connell

Postgraduate Researcher

Department of Geography and Planning

University of Liverpool

e-mail: yelenam@liverpool.ac.uk

Tel: 0151 795 2808

Project supervisors: Dr Bethan Evans, Dr Mark Riley Department of Geography and Planning, University of Liverpool; Prof Christine Milligan, Division of Health Research, Lancaster University